Training Manual for MR/DD Services – Targeted Case Management

Table of Contents

Introduction and Acknowledgements

Greetings! This training manual is the first edition of this effort to combine and provide core training materials for people who are providing, or seek to provide, case management services to Kansans with developmental disabilities. The guiding values for this manual were developed by an extensive stakeholder effort, involving the combined experience, wisdom and practical considerations of nearly 100 case management practitioners, other community service providers, people receiving services and their advocates, provider association staff, Community Developmental Disability Organization staff, and staff from Health Care Policy/Community Supports and Services.

The preparation of this training manual likewise was the combined effort of these types of stakeholders, building many details upon the foundation of the previous guiding effort and the years of experience in delivering case management services in Kansas. Specifically, the people responsible for the development of this training manual are as follows:

> **Assessment Module** – all issues except positive behavioral supports. This includes both formal and informal assessment activities.
>
> > Team members:
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> > > Ida Kerbs, COF
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> **Support Planning Module** – all issues except positive behavioral supports. This includes person centered support plans; team building/leading; maintaining relationships with support teams; meeting facilitation; communication skills; informed choice vs. risk; transition planning; and, building next best options.
>
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> > > Sallie Jensen, KETCH (team facilitator)
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> **Positive Behavior Supports Module** – this includes, in the arena of positive behavioral supports, formal and informal assessments; least restrictive practices; informed consent; environmental or service modifications; psychotropic medications; mental health/dual diagnosis issues; and, effective implementation techniques and support strategies.

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Support Coordination Issues Module – this includes advocacy/access issues (criminal justice system involvement, guardianship/alternative decision making, benefits, basics of waiver/non-waiver services, plans of care, temporary specialty services); individual rights and related responsibilities; natural supports; generic services.

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Monitoring and Follow Up Module – this includes support plan implementation; utilization of the KLO 2nd tool; and, abuse, neglect and exploitation issues.

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Supporting Children and Families Module – this includes benefits, services and resources unique to children; individual education plans; infant and family service plans; transition planning; children in SRS custody/foster care; and children residential services.

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Finalizing Team – this including taking the training modules drafted by the teams described above, reviewing/modifying them to ensure consistency and reduce redundancy, putting them in final form and developing the process for web-based training and assessment.

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To each of these dedicated professionals, Health Care Policy/Community Supports and Services – on behalf of stakeholders widely – expresses sincere appreciation for the commitment of their time, experience and talents.

We welcome feedback concerning this manual, and offer it in the spirit of enhancing the delivery of case management services statewide. We will continue to review and enhance this effort over time.

If you have feedback about this material, or **if you need accommodation of any kind** in order to access and utilize it, please contact Lizz Phelps, HCP/CSS, at 785/296-6140 or lmp@srskansas.org.

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Module 1: Assessment

Value Statement
It is crucial to get the most accurate information as possible. Therefore it is important for the person completing the assessment to get the information as directly as possible. Face to face contact is preferable with phone contact being acceptable if necessary.

BASIS Assessments

The Case Manager's Role
First and foremost it is the Case Manager's role to advocate on behalf of the person served.

Prior to completing BASIS Assessments, the Case Manager must obtain and maintain BASIS Certification through Health Care Policy.

Prior to the assessment
- Coordinate with the person's support network to schedule BASIS Assessment meetings/interviews.
- Review documentation to ensure it is sufficient to verify the information being reported and that it is easily accessed.

During the Assessment
- BASIS Assessment interviews, as feasible for the individual, should be held in person with the person served and in person or by phone with the guardian and any other members of the person's support network that would have relevant information. <u>ALL</u> attempts should be made to ensure participation by the guardian and person served.
- If the Case Manager becomes aware that someone is inaccurately reporting information (either not wanting to talk badly about a person served or in hopes of inflating the tier rate), the Case Manager must take steps to ensure the purpose of the BASIS Assessment and the necessity of accurately reporting needs are protected.
- Assist in completing BASIS Assessment (unless completed by the local CDDO).

After the Assessment
Ensure that BASIS Assessments are submitted to the CDDO to be transmitted to Health Care Policy during the person's birth month, unless otherwise specified by the CDDO.

Throughout the Year
- The Case Manager should gather and document information from the person served, parents/guardians, schools, community resources, caregivers, mental health professionals, physicians, etc. to ensure accurate information is reported.
- Complete and submit to the CDDO BASIS Sections 4, 5 & 6 during the person's birth month and again 6 months after the person's birth month.
- BASIS Section 1 must be completed and submitted to the CDDO as soon as changes in guardian, address or other information occurs.
- BASIS Section 3 must be completed and sent to the CDDO immediately when changes in services or service needs occur. BASIS Section 3 would also be completed if a service is anticipated to be requested in the next 3 years.

The Value of BASIS

Section 1- Information
It is very important that the information in Section 1 is as current and accurate as possible. This information is used by Health Care Policy, the Legislature, community service providers, and CDDOs to determine service needs.

Section 2- Developmental Disabilities Profile
The Developmental Disabilities Profile has a direct impact on funding and helps identify support needs for the Person Centered Support Plan. Tiers obtained must accurately reflect the individual's needs so that the person can have the necessary supports, but not more supports than are needed. When one person served has more than they need, another individual goes without. (Fiscal responsibility)

Section 3 - Services
This information is used to develop the Services Access list. It is imperative that this information is current and accurate. The Services Access list is used to identify who is served and underserved, and who is waiting for services in order to accurately project funding and service needs.

Section 4 – System Analysis
This information helps the Case Manager, community service providers, Health Care Policy and CDDOs identify if people with disabilities are experiencing unequal access to Health services. It identifies how many people are currently living in ICF/MR's and want to move into the community. It also identifies Residential and Day attendance which helps Health Care Policy determine how much funding is needed.

Sections 5 & 6 – Psychotropic and PRN medications
This information is used by Health Care Policy, the Legislature, community service providers and CDDOs to identify general trends in medication usage and that psychotropic medications are being used effectively.

Needs Assessments

A formal needs assessment, as determined by the CDDO, is required when services are involuntarily decreased and can be required by the CDDO at any time. Case Managers should do informal needs assessments whenever services are discussed with the person served or the support network to determine service needs.

Informal Assessments

Case Managers complete formal assessments such as those discussed here, but also informal assessments. When visiting a individual at home or in the community, the Case Manager is really assessing the quality and responsiveness of the services being provided and the person's level of satisfaction with the services they receive including the implementation of their Person Centered Support Plan. The Case Manager documents and gathers this information by observation, phone calls, reviewing other support team or other agency documentation, visiting with providers, school professionals, families etc.

Risk Assessments

Purpose
The purpose of a risk assessment is to assist individuals served and their guardians in understanding negative consequences of known choices the individual might make and which may involve risk to that individual. (K.A.R. 30-63-21 #4 A, B & C)

When a risk assessment is necessary
When previous interventions have been tried and fail and it may become necessary to restrict an individual's rights in order to protect their safety and/or the safety of others. The Case Manager shall describe to the individual and their team how his/her lifestyle choices may be limited because of imminent danger to the individual's health, safety or well being. (K.A.R.30-63-21 #5 A, B, C, & D)

Some examples of when a risk assessment might be necessary
- If, during the individual's team meeting or at any other time, there is concern with the individual's history of decision-making and ability to understand consequences and there are potential negative consequences to the individual's lifestyle choices.
- If information reported leads the Case Manager or a member of the support network to make a decision to do so. For example, if a provider, out of concern for the individual's safety has implemented a restrictive intervention that has not been discussed by the support network.

Who should be included in a risk assessment?
All attempts must be made to include the person served and their guardian. However if the person served/guardian are unable or unwilling to participate, a risk assessment must still be completed when a concern has been identified. The guardian must approve the risk assessment in writing prior to the implementation of restrictive interventions. Restrictive interventions must also be approved by the Behavior Management Committee in accordance with the safeguards of K.A.R. 30-63-23.

The risk assessment must also include input from the individual's support network.

While assessing risk, information can be obtained from these sources by informal/formal means (by phone, meetings etc.).

A risk assessment must include (K.A.R. 30-63-21 #5 A, B, C, & D):
- A statement of the issue. – What is the questionable choice being made and why is it a concern.
- History of decision making – Describe what has led up to the present risk assessment. This should include: a.) Incidents of the behavior or medical issue that is being addressed. b.) The person's ability to learn from natural and negative consequences of poor decision making as shown by previous experiences. c.) It is important to state what has been tried in the past, and been unsuccessful. When reviewing behavior related risk assessments, Behavior Management Committees will be reviewing whether or not there have been other interventions tried before imposing a restriction.
- Possible long and short term consequences – A risk assessment should address what could happen if there is no intervention and the person makes a poor decision. For instance, involvement with law enforcement, financial hardship due to refusal to work, etc.
- Possible long and short term effects of imposed limitations – State the effects that might result if the team limits the individual's lifestyle choices, and what will happen due to the imposed limitation. For instance, someone who is being restricted may become angry or feel disrespected because of a decrease in independence.
- Safeguard/supports discussion – State what supports and safeguards are in place to protect the person's safety and rights.

Module 2: Support Planning - Developing a Person Centered Support

Plan

Note: This is very brief and cursory information about key issues involved with person centered support planning. It is not designed to inform you about everything needed to develop a thorough person centered support plan. You should obtain necessary training about both substantive and format information for the area you provide services and the people you support, and ensure that you are able to effectively support the development of these very important tools.

Pre-Meeting Planning
- Pre-interviews with the person-
  It is important to meet with the person you support prior to the development or planning meeting of supporters for input into the person centered support plan. Some of the issues to review and discuss with the person are:
  ▸ Who do you want at your meeting?
  ▸ Where do you want to have the meeting?
    (#1 a, b, and c are from Regulation 30-63-21 #1 a, b, c)
  ▸ When do you want to have the meeting?
  ▸ You should work with the person to become aware of key lifestyle preferences prior to a planning meeting. Discuss with the person his or her key lifestyle preferences – and the values upon which they are based – including a consideration of the following:
    (from Regulation 30-63-21 #2 a, b, c, d, e)
    ꙅ In what type of setting do you want to live;
    ꙅ With whom do you want to live;
    ꙅ What work or other valued activity do you want to do;
    ꙅ Who do you want to socialize with; and
    ꙅ In what social, leisure, religious, or other activities do you want to participate.

    It is also necessary to discuss, and ultimately develop a listing of, the necessary activities, training, materials, equipment, assistive technology and services that are needed to assist the person to achieve the person's preferred lifestyle. This should include paid, unpaid/natural and generic community services and supports which can be accessed by the person. These are very important parts of a good person centered support plan which will serve as a guide to successful services and supports for the person; the listing/description of needed supports – together with any barriers to achieving them, and strategies to overcome those barriers – is an essential part of person centered planning.

  ▸ Are there certain things you don't want to discuss at the meeting. Who do you want to facilitate the meeting – Anyone on the team can do this.
    (from Regulation # 8 b)
  ▸ What help do you need from me with participating in your planning the meeting (i.e. an interpreter for you or any team member, or any other adaptive devices)
    (from Regulation 30-63-21 #4 a, b, and c)

- Be sure all support staff and family/guardian are invited to the meeting or provided an

opportunity for input. Individuals not invited or unable to attend the meeting will be given input by an interview with the TCM or by filling out a blank question form.
(Regulation 30-63-21 #1 B)

- Review all available information over the past year to help identify trends or issues that may need to be addressed – i.e. Satisfaction surveys, assessments, behavior data, case notes, etc.

- Secure a meeting place and let all those invited know the location and time.

- Prepare an agenda. Gather other needed materials for the meeting.

- Determine who will be writing the Person Centered Support Plan also.

The Meeting
- Facilitation of the meeting:
  - ▸ Introductions
  - ▸ Explain the purpose of the meeting.
  - ▸ Review roles and expectations for meeting participation to enhance team building, relationships and communication.
    - S Know the individual with whom you are working.
    - S Come to the meeting prepared to discuss the individual's progress, problems, concerns, and accomplishments to celebrate.
    - S Share your information in the meeting in the same way you would want information about you shared with others.
    - S The process is individually driven/individualized.
    - S Tone should be kept positive, respectful, and outcome oriented.
    - S Traditional roles will be respected but be prepared to think outside the box.
    - S All team members are expected to attend on time and stay for the duration of the meeting.
  - ▸ Assure the meeting is the person's meeting and doesn't turn in to the team's meeting.
  - ▸ Have a game plan of working toward meeting the person's preferred lifestyle through goals where applicable.
  - ▸ Keep in mind the financial impact of services as options may possibly be presented. (from Regulation #7 b i), and be prepared to explore and develop next best options based on the values driving the person's choices, the related needs, and an expansive consideration and potential alternatives which will honor the core values.
  - ▸ At the close of the meeting, ask the person if the team got it right and if there is anything else that needs to be discussed.
  - ▸ Thank everyone for attending.

After the Meeting
- Continue to communicate with all team members to assess progress and bring the team back together to possibly revise the plan as needed. (from Regulation 30-63-21 #8 c)
- Review all documentation on progress of goals to determine if progress is being made.

- The provider shall regularly review and revise the plan, by following the same procedures as set out above, whenever necessary to reflect any of the following:
  ‣ Changes in the person's preferred lifestyle;
  ‣ Achievement of goals or skills outlined within the plan; or (from Regulation 30-63-21 #6)
  ‣ Any determination made according to the methodology provided for in paragraph below that any service being provided is unresponsive.

  Contribute to the continuous movement of the person towards the achievement of the person's preferred lifestyle. In evaluating this outcome, the provider may include assessments made by professionals and shall perform either of the following:
  ꙅ Include consideration of the expressed opinions of the person,
  ꙅ the person's legal guardian, if one has been appointed, and
  ꙅ other individuals from the person's support network.

- Whenever a revision is needed to the Person Centered Support Plan it must "be approved, in writing, by the person or the person's guardian, if one has been appointed. Requirements for approval from or consultation with the person's guardian shall be considered to have been complied with if the provider documents that it has taken reasonable measures to obtain this approval or consultation that the person's guardian has failed to respond."
  (from Regulation 30-63-21 #8)

- The Person Centered Support Plan is a working document that needs to be updated and revised as the person served life changes or as needs change.

Meeting the Preferred Lifestyle, Barriers to That, and How to Achieve the Next Best Option

- Persons served identify their preferred lifestyle of where they want to live, who they want to live with, who they want to socialize with, what they want to do as a valued activity or work, etc.
- After that is identified the team evaluates if that is being met or what is keeping that preferred lifestyle from being met. These would be barriers.
- Then the team will identify how we can meet the preferred lifestyle by overcoming the barriers if possible at this time. While the barriers may be keeping the person served from meeting their preferred lifestyle, identify the next best option if the preferred lifestyle cannot be met.

Example:
John stated that he wants to live in an apartment by himself without staff support. John has medical limitations of severe seizures and recent head trauma that require him to have assistance in bathing, using the restroom, taking his medications, and overall monitoring of his medical conditions for his safety. John does not earn enough money in his work or from benefits in order to live on his own at this time. The preferred lifestyle is that John wants to live in an apartment by himself without staff support.

The barriers to that preferred lifestyle are that John's medical needs require that he have

assistance for his safety and well-being with bathing, using the restroom, taking his medication, and over all monitoring of his medical conditions. Another barrier is that John does not make enough money to support him financially.

After that is identified the team will need to brainstorm as to how we can help John reach his preferred lifestyle. Could John get a job from which he makes more money? Are there any assistive technologies to help John be able to take care of his daily needs by himself? Explore with John the key values behind his preferences and ways to meet those values. Are there ways to enhance John's privacy and independence that will also support his safety? If the team does not find that any of those strategies are feasible at this time, what are some ways to work toward the values, and what would be the next best option for John as far as his lifestyle goes at this time?

Identify the next best option. All of this process should be identified in the Person Centered Support Plan. Remember that at any time revisions and updates can be made to the Person Centered Support Plan (from Regulation 30-63-21 #8 C)

Examples of conflict resolution for next best options for change in services:

- ▸ Ask the person served and guardian what values are driving the request for change in services.
- ▸ Brainstorm with the team as to how the team can assist with meeting the preferred lifestyle.
- ▸ Complete a needs assessment.
- ▸ Explore with paid providers about current or feasible additional options for effective services.
- ▸ Give options of other services/providers or community/natural supports that may be able to assist in being responsive to the preferred lifestyle.

Informed Choice Versus Risk

Definition of Choice: The act of selecting an alternative, based upon understandable substantive information about available options.

Definition of Risk: The possibility of danger, injury, loss, etc. The possibility of putting oneself in danger, injury, loss, etc.

- • When supporting someone in making key lifestyle preference decisions, the case manager should assist the person in having current, substantive and understandable information about all available options.
- • When making these choices, if risk in involved, the case manager should support the person in being aware of the nature of the risk and the impact of the risk upon the person's lifestyle preferences. (from Regulation 30-63-21 #4 A, B, C)
- • If a person's lifestyle choice may create imminent significant danger to the person's health, safety or welfare, a risk assessment needs to be completed.
- • A risk assessment needs to include:
  (from Regulation # 5 A, B, C, D)

- ▸ Describe when it is necessary to do so, to the person and the person's support network how the preferred lifestyle might be limited because of imminent significant danger to the person's health, safety, or welfare based on an assessment. This includes an assessment of the person's history of decision making, the possible long- and short-term effects if the person makes the decision and if the person is limited or prohibited by a provider from making the choice, and the safeguards available to protect the person's safety and rights in each context of choices. SEE REGULATION 30-63-21 # 5 A, B, C, and D)

- ▸ These choices and risks involved may be part of the existing Person Centered Support Plan or may develop at any time. When situations of choice or risk present contact the team (via phone, e-mail, face to face, etc) for input and revise the plan as needed. Guardian (if appointed) and person served approval only needed. Assure that all team members are informed of the changes and have a copy of the revised changes in the Person Centered Support Plan.

Other Conflict Resolution Strategies

Other Conflict resolution strategies regarding issues that may come up during a meeting with the team that do not deal with the issues at the meeting or the Person Centered Support Planning at that time:

- Acknowledge the issue being brought up and ask if it could be addressed one-on-one during break.
- Remind the team the purpose of the meeting.
- If issue still arises, pull out your calendar and set a date for a meeting to discuss the issue.
- If issue still arises, call for a break and address it right then.

Transition Planning

- For types of transitions and planning needed refer to regulation 30-64-24 #5 A, B, C, D, & E.
- In transition planning the role of the Case Manager is to support the person in effectively identifying and achieving his/her needs and preferred lifestyle (refer to regulation 30-63-21 # 2 A, B, C, D, and E)
- When supporting a person who is transitioning services, remember to keep any/all team members that are in the team and that will be a new or additional team member involved. Communication is the key to smooth transition.
- Transition planning may be needed at any time, not necessarily at the time of a periodic review of the Person Centered Support Plan. The plan may need a revision for the transition.

Module 3: Positive Behavior Supports

Note: The purpose of this module is to provide some basic overview information about key substantive issues involving positive behavioral supports, as well as regulatory and service standards. This module is not designed to make you, as the case manager, qualified to create,

develop or write complex behavioral support programs. If the person needs more intensive formalized behavioral support programming than you are otherwise qualified to effectively create (by virtue of other training, education or experience you have gained), you should assist the person and his/her service providers in locating and accessing qualified behavioral professionals.

Introduction

Mary constantly complains when she goes in to the day service center. On an unpredictable basis Sally falls kicking and screaming onto the floor when heading toward the break room for lunch. Mark yells whenever someone reminds him to take a shower. Sara picks at her skin. David routinely slaps himself in the face for no apparent reason. Do any of these types of situations sound familiar? You might know someone whose behavior creates difficulties for them and often for the people around them.

People with developmental disabilities who engage in serious problematic behavior present us with some of our greatest challenges. Traditional approaches to "manage" these types of issues are often ineffective, primarily for two reasons. First, commonly used techniques "pay little attention to understanding"
- who the person is,
- what the social contexts for behavior are, and
- what function or purpose the problematic behavior serves.

Second, traditional management procedures have placed exclusive emphasis on using unpleasant consequences to suppress or control the person's behavior, rather than teaching and reinforcing socially appropriate alternative skills." (Designing Positive Behavior Support Plans by Linda M. Bambara & Tim Knoster).

Experience has proven that the person-centered support plan is the starting point and the foundation for all positive behavioral supports. Through the person-centered planning process, the person and their support team can begin to identify interests, strengths, preferences, communication methods, and support needs. It is critical for the people who are responsible for supporting the individual to also have detailed information about skills and limitations, such as level of ability with different tasks, physical limitations, how the individual responds in different situations, etc. This information should be incorporated into the person's daily routine and may prevent or greatly reduce the problematic behavior. Consideration of these preferences should always occur prior to the implementation of interventions that restrict the rights of the person. However, if the person continues to engage in a problematic behavior that involves imminent, significant danger to the person's health, safety, or welfare it may be necessary to develop positive behavioral supports that include restrictive interventions. Although these types of support plans are often quite detailed and may be developed by an individual who has specific training in behavior analysis, they should compliment and be considered a part of the regular person-centered planning process.

Positive behavior supports encourages a person to learn and retain lasting behavior change. The focus changes from "managing" the behavior to "understanding the person and the function the behavior serves for the person." A lifestyle change occurs because positive behavior supports are grounded in person-centered values that respect the dignity, preferences, and dreams of each person. More than a technology to reduce problematic behavior, positive behavioral supports focuses on treating all people, regardless of their level of ability or nature of their challenging behavior, with the same respect and dignity we hold for ourselves and focuses on outcomes that are important to the person. Positive behavioral supports facilitates opportunities, such as new or improved friendships, use of natural supports, improved social relationships and participation in community

activities. The result fosters independence and productivity and allows the person further integration and inclusion in his or her natural community. We work to provide opportunities for people to fully exercise their right to live and work in their chosen community.

Community normative behavior is an essential element to a person's acceptance in their natural environment. Positive behavioral supports provide an increased opportunity for successful integration and inclusion of many persons with difficult behaviors. Some individuals may present behavioral problems due to medical and/or mental illness. Simultaneous to the implementation of positive behavioral supports, team members should seek thorough medical, neurological and/or psychiatric evaluations to determine other potential causes for the behavior .

Behavioral Approach

We all have behaviors. They start when we are born and continue the rest of our lives. Most of our behaviors are generally accepted in our communities, while others are not. Some of our behaviors are vocal or verbal, like crying, sighing, yelling or cussing. Others are physical, like stomping our feet, kissing, throwing things, hugging, slamming doors, hitting, patting on the back, pinching, and walking off. Some are positive, like telling someone you like or love them, while others are negative, like saying, "I hate you" or "Bug off". Many of them are learned because our siblings, parents, teachers and peers unknowingly teach them to us.

If we take a minute, and think about it, we realize our behaviors just don't happen. We decide to do them. We do them with a purpose and a desired outcome in mind. We cry to get our mother to come over and feed, or change or pick us up. We cry because we want someone to give us the toy they have, or give back the toy they took from us. We cry because someone hurt us and we want him or her to feel sorry or know that making us cry will get him or her in trouble. We cry so someone will leave us alone and we can escape our predicament. Just as there are reasons we cry, there are reasons we perform all sorts of verbal and physical behaviors.

There are various reasons we perform behaviors. We use behaviors to get attention, to get what we want, to escape, to take control of the situation, to increase or decrease stimulation, such as pain or enjoyable sensory stimulation, among others.

There are many different behaviors we can use to get what we want or to achieve the same outcome. There are behaviors that don't work with certain people or don't seem appropriate at the time. Thus, we need a repertoire of behaviors so we can shift to one that works.

When working with persons who need significant behavioral supports, we must think about reducing or eliminating the problematic behavior.   As we evaluate the most appropriate way to make this change, consideration should be given to the following:
- changing environmental conditions or circumstances
- evaluating and ruling out possible medical or physical barriers
- increasing consistency in support implementation
- the need to retrain staff
- assessing skill level to determine if the person is capable of doing what we are asking them to do, and
- changing our expectations.

If adjusting these issues does not positively affect the problematic behavior, we may need to replace the undesirable behavior with a more acceptable behavior that still allows the person to get what he or she wants.

When working with persons who communicate their wants and needs by using behaviors we know are not appropriate, we first need to determine the reason the person uses the behavior and then give him or her an alternative, effective way to communicate. This is called Functional Communication Training or FCT. FCT is the assessment of why the person uses the problematic behavior and the teaching of a more appropriate form of communication that achieves the same desired end. For example, a young lady with autism was pinching her teacher. The teacher was standing beside her, during a break, with a sack of salted peanuts in her hand. Observation suggested she was interested in getting a peanut to eat. The young lady was taught to tap the teacher on the arm and imitate the word "peanut", and eventually spontaneously ask for a peanut. The problematic behavior, pinching, stopped as the young lady was taught to use an alternative method to get what she wanted and reinforced for using the alternative behavior: tapping the teacher on the arm, saying "peanut" and being handed a peanut to eat. This appropriate alternative behavior was taught in other situations where pinching was used by the young lady to gain attention and get what she wanted.

When the person cannot talk, we use communication devices (AAC or Augmentative/Alternative Communication devices) so he or she can point to a picture or word that tells their listener what they want, need to do, what bothers them, or what they don't like.

When the person can talk, we tell the person to repeat or name what they want or need, instead of accepting and rewarding the problematic behavior.
To initiate the resolution of problem behaviors presented by individuals we work with, we must first perform an assessment called a Functional Behavioral Analysis (FBA) of the problem behavior. We must take the time to collect the needed data to define the elements and function of the problem behavior and derive at a program for replacement of the problem behavior with an appropriate, efficient, alternative behavior.

Assessment

After we identify a problematic or undesirable behavior and before we attempt to teach an alternative replacement behavior, we must clearly assess the function of the problematic behavior. This type of assessment is often called a Functional Behavior Analysis (FBA). Detailed data is collected to assist our understanding of the structure and function of the behavior and allows us to discover what the problematic behavior accomplishes for the person. This type of assessment is critical to the development of effective positive behavioral supports.

An assessment includes, at a minimum:

• a specific and detailed description of the behavior

• a review of previous and present medical status

• a description of the setting where the behavior occurs; who is present, what is happening, where it is happening, and when it happens

• how long the behavior lasts

• how intense is the behavior (mild, moderate, severe)

• the antecedents/predictors that trigger the behavior (a room crowded with people; the appearance of the driver that takes him or her to work; a hypodermic needle, etc.)

- the precursors of the problematic behavior (she spins around before she hits you; he belches just before he vomits; she sings when she is going to slap her head; etc.)

- consequences of the behavior; what is the person getting as a result of the behavior - attention, control, escape, needs met, etc.

- what is the person trying to tell you/communicate to you - I need to talk to you, I want out of this situation, I need help, etc.

- is the appropriate behavior and effective/efficient way for the person to get what they want; how much physical effort does the behavior require; does the person hurt him or herself; does he or she have to repeat the behavior over and over before it is understood; does the behavior have a lot of steps that have nothing to do with targeting the desired goal of the user; do people walk away when the behavior appears and the user has to follow them; does the behavior require alterations to reach the wanted effect; etc.

- what are some alternative, appropriate behaviors the person could learn to use instead of the problematic behavior to get what they want

- how does the person communicate, including verbalizations, facial expressions, gestures, behaviors, etc.

- what are the persons preferred reinforcers, what makes the person feel good, what will they work for, what will motivate the person to make a behavior change

- history of the behavioral issue and attempted solutions

To complete an effective and useful assessment, meaningful data needs to be collected. Meaningful data reflects information such as: whom the behavior happens with, where the behavior happens, what happened just before the behavior occurred that might signal or be a trigger for the behavior, what the person is doing or is supposed to do next that they are anticipating and reacting to, etc. You are looking for the reason the person performs the problematic behavior.

Concurrently, we make a list of the places, settings, situations, activities, and persons' where the undesired behavior seldom, if ever happens. In many instances, by manipulating the environment, the activity or the behaviors of other persons in the setting/situation, the problematic behavior may no longer be needed by the person. Increasing the time the person attends activities in environments where the problematic behavior is not needed, can alleviate or eliminate the use of the problematic behavior. By changing the interactive modes of persons in the setting, the problematic behavior may not be elicited. By giving the person choices instead of directives, the problematic behavior may be evaded. As we learn how behaviors work and what they mean, we decide whether to address them or leave them alone. If we want the person to use the alternative, more socially appropriate behavior across various settings, we must teach across multiple environments so the person can generalize the information.

As you collect data, you discover what variables are present that do or do not cause the undesirable behavior. You discover what specific subject to mention, which object to present, the way to look at the person, a certain item to remove, what person to bring into the setting, what task provokes the person to engage in the undesirable behavior, etc. You are learning the person's preferences and the elements you need to develop an effective positive behavior support plan for that individual.

Behaviors, unless they are physiological, happen for specific reasons. We use behavior to communicate to other people, just like we use verbalizations and sign language. Some of the reasons for using various behaviors are to communicate the following:

- to escape a situation
- to gain control of a situation
- to get attention
- to increase the chance of getting what you want
- to decrease the chance of getting what you do not want
- to get stimulation

When you determine what function the behavior serves, you can then determine an effective way to eliminate the behavior.

When you think you know why the person uses the behavior, test out your assumption. If the person uses the behavior to gain attention, you might turn your back on the person and see if the behavior increases to get your attention or just stops. You might notice the behavior happens when you give your attention and stops when you are not attending or when you leave.

If you think the behavior occurs when the person wants to escape or get out of a task, present the task and see if the behavior occurs. Remove the task and see if the behavior stops.

If you think the person uses the behavior to get what he or she wants, give the person the wanted item and take the item away. If the behavior stops then starts again, the person uses the behavior to get wanted or needed items. This information is also helpful when you plan reinforcers to use with the person to assist with motivating the behavior change.

With this knowledge, we know why a person uses a particular behavior, what causes the behavior and when the behavior is likely to occur. You actually know how to cause the person to use the behavior. In other words, you will know what purpose the behavior serves for the person, what they are trying to tell you and what motivates the person to act.

When selecting an alternative to the problematic behavior, choose one that is easy for the person to learn, recognizable by the listener, interpretable by the listener, and results in a more immediate reinforcer for the person. When you decide what alternative to teach , you must work on reinforcing the new behavior and eliminating the problematic behavior. One way this can be done is by giving the person what they want only when they use the appropriate alternative behavior and never give it to them when they engage in the problematic behavior.

You continue to take data to demonstrate that the positive behavioral supports are working. If the behavior stops or decreases, continue with the positive behavior supports. If not, the data will indicate a need to re-analyze and revise the supports. Don't frustrate yourself or the person with the problematic behavior by continuing to implement ineffective supports.

It is not unusual to observe an increase in the frequency and magnitude of the problematic behavior when we first attempt to change or replace it. The person using the problematic behavior to achieve their desired outcome may be confused by the sudden ineffectiveness of the time proven behavior and think they must scream louder, pinch harder, or bite themselves more severely to achieve what they want. It only takes days or a few weeks to determine if a consistently applied program is

working or not.

Results of completing a quality functional behavioral analysis may include:

- The gain of information needed to develop credible, effective support for the person.

- Gradual or immediate reduction in the problematic behavior as a result of positive behavior supports developed specifically to meet the person's needs

- Potential for psychotropic medication reduction

- Staff feels competent in working with persons with problematic behaviors and provide consistent support

- Increase staff usage of Functional Behavioral Analysis and Functional Communication Training thereby contributing toconsistent and effective support and planning

- Reduction in restrictive measures used with the person

- Progress in the person's ability to become independent and productive

Assessment of Risk

When an individual, engages in behavior that poses risk to their (or someone else's) health, safety or well-being an assessment of risk should be completed. This is completed as a means to: evaluate the risk of certain behaviors; document what is being done to educate or protect the individuals effected by the risky behavior and to inform an individual or their guardian (if applicable) of how the individual's lifestyle might be limited if they continue to engage in the risky behavior or if a particular intervention is utilized. It may or may not lead to a decision to restrict the individual's rights. In some cases, an assessment of risk may simply document that the agency addressed the issue with the individual and acknowledges the individual chooses to continue with the behavior regardless of the risk involved. An assessment of risk should address the following:

- a detailed description of the risk issue
- the individual's history of decision-making (including any previous experiences in that area of decision making and the person's ability to learn from the natural negative consequences of poor decision making);
- the possible long and short term consequences that may result if the person makes a poor decision;
- the possible long and short term effects of increased direction and control by care givers and
- assure available safeguards to protect the safety of the individual and other's whom the individual's behavior may effect.

If the intervention is such that it does not restrict an individual's rights, then listing it as a support in the person's support plan may be sufficient. The support should state what the issue is, what is being done and that it is something the individual wants to do. For example, you may assist someone to avoid caffeinated drinks by providing the support of not having it around and helping them make healthy choices when presented with the option of caffeinated products. If there is potential for someone's rights to be restricted, then an assessment of risk may be the best route. However, for interventions that require procedural structure for consistent and effective

implementation a formalized behavior support plan is recommended. If the team decides to intervene with the behavior that is causing the risk by limiting the individual's rights, then voluntary informed consent must be obtained by the individual, or their guardian, if one has been appointed. If an agency is unable to obtain a response from an individual's guardian, regulatory compliance will be acknowledged given reasonable measures have been taken to obtain the consent. The intervention must also be reviewed by the behavior management committee (third party review).

Refer to K. A. R. 30-63-23. Medications; restrictive interventions; behavioral management committee for further information.

Planning Positive Support Strategies

Positive behavior support plans should be written because an individual is engaging in problematic or disruptive behavior that is a barrier to their independence or relationships with others. It should be noted that behavior is a means of communication. What the person might be communicating is pain, fear, boredom, illness or any other emotion. By "acting out" or engaging in a problematic behavior the person is trying to gain something they want. This is a reinforcer. Reinforcers can be as varied as what a person may be wanting to communicate from their behavior (attention, avoidance, control, etc.). In some cases the individual may not even realize that there are other ways to get what they want.

As noted above when an individual uses a problematic behavior there is a reason why the person is using it. Through functional analysis, observations and trial and error we may find out the purpose of an individual's behavior. The point of the positive behavior support plan is not to take away what that person is trying to get, but to teach them a more socially acceptable and normative way of getting it. This is what leads to the key elements in a positive behavior support plan:

Consideration should be given to retraining staff, increasing consistency of positive support implementation, changing environmental conditions, ruling out medical or physical barriers, reassessing skill level to see if the person is capable of doing what we are asking them to do, and changing our expectations. Making changes in these areas need to be evaluated before planning further. Many times the least restrictive intervention is one that makes changes to the environment or people around the person being served. Such changes can sometimes eliminate the need for further intervention.

What is the behavior we want to change? The behavior has to be described specifically in the positive behavior support plan. It is important that everyone working with the individual is looking for (and consistently identifying) the same behavior. This makes tracking of the behavior easier. It also makes the plan more effective because all persons can consistently respond to the behavior. What is the appropriate behavior desired to replace the inappropriate behavior? As noted above, an individual's behavior is usually an attempt to communicate or get a desired outcome. The purpose of the positive behavior support plan is not to deny someone something they may want or need. It is to teach them to ask for what they want in a more socially normative manner. The plan should explain an appropriate way the person can get the outcome they desire and how the support staff will teach the alternative behavior, including how the staff will respond when the undesired or problematic behavior occurs. In some cases the person themselves may not know what exactly they want (or gain) from an inappropriate behavior. In this case reinforcers may need to be put in place so an individual can easily identify positive outcomes with appropriate behavior.

What are the time frames being measured for success (or failure) of the plan? When a formalized plan is being used there has to be some measure of success for that plan. That is why it is important

to specifically identify what the behavior is so it can be accurately tracked. Time frames should also be put in place to review the plan to identify whether a person has learned the new appropriate behavior or is not making any success in changing the inappropriate behavior.

What has been done to ensure that the plan is using the least restrictive process? As noted before, a positive behavior support plan is usually written because an individual is exhibiting a problematic or undesired behavior that is a barrier to the person's independence or relationships with others. Sometimes the solution can be very simple, like moving the individual away from another individual that upsets them. Or teaching the person to use a normal voice tone when asking for assistance rather than screaming. Other times it requires restrictions and negative consequences to extinguish an existing behavior before the individual is willing to learn a new appropriate behavior. In the latter case medications and limitations of rights may be put in place. The plan MUST document what lesser restrictive measures have been tried before the present procedure was implemented. This can be information regarding changes in environment, how supports were modified and reinforcers that were tried but not completely successful.

Dual Diagnosis

What is Dual Diagnosis?
In the various Social Services programs Dual Diagnosis may have different meanings (e.g. in mental health, dual diagnosis may mean Mental Illness with Substance Abuse). In the Developmental Disability area this usually means someone who has a mental illness and a developmental disability.

What is Developmental Disability?
Consistent with K.S.A. 39-1803 (f) and (h) persons who are mentally retarded or otherwise developmentally disabled are those whose condition presents and extreme variation in capabilities from the general population which manifests itself in the developmental years resulting in a need for life long interdisciplinary services. The following identifies those who, among all persons with disabilities, are the most disabled, as defined below:

Mental retardation means substantial limitations in present functioning that is manifested during the period from birth to age 18 years and is characterized by significantly sub-average intellectual functioning existing concurrently with deficits in adaptive behavior including related limitation in two or more of the following applicable adaptive skill areas:
- communication
- self-care
- home living
- social skills
- community use
- self-direction
- health and safety
- functional academics
- leisure
- work

Other developmental disability means a condition such as autism, cerebral palsy, epilepsy, or other similar physical or mental impairment (or condition which has received a dual diagnosis of mental retardation and mental illness) and is evidenced by a severe, chronic disability which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments, AND
- is manifest before the age of 22, AND
- is likely to continue indefinitely, AND
- results in substantial functional limitations in any three or more of the following areas of life functioning:

  ▸ self-care
  ▸ understanding and the use of language
  ▸ learning and adapting
  ▸ mobility
  ▸ self-direction in setting goals and undertaking activities to accomplish those goals
  ▸ living independently
  ▸ economic self-sufficiency, AND

  To further clarify substantial functional limitations the CDDO may, but is not required to, use The Eligibility Determination Instrument (EDI) in Mental Retardation Services, Division of MR/DD Services, Case Management Handbook.

  ▸ reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong, or extended induration and are individually planned and coordinated, AND

  ▸ does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill or have disabilities solely as a result of infirmities of aging.

What is Mental Illness?
Mental illnesses are severe disturbances in behavior, mood, thought processes and/or interpersonal relationships. The Diagnostic and Statistical Manual of Mental Disorders (DSM IV, 1994) list the different types of mental disorders.

The types of psychiatric disorders persons with developmental disabilities experience are the same as those seen in the general population, although the individual's life circumstances or level of intellectual functioning may alter the appearance of the symptoms. Some of the common types are:

Affective Disorders: These disorders are predominantly characterized by disturbance of mood. Depression, bi-polar and mania are the major sub-categories of affective disorders.

Psychotic Disorders: This group of disorders is characterized by the presence of delusions, hallucinations, disorganized behavior and/or impairment in reality testing. Schizophrenia, schizoaffective and schizophreniform are some of the major sub-categories of psychotic disorders.

Personality Disorders: This group of disorders refers to an enduring pattern of dysfunctional behavior. Symptoms frequently found are personality traits that are inflexible and maladaptive and cause significant impairment of subjective distress. Paranoid, anti-social, borderline and avoidant are some of the major sub-categories of personality disorders.

Anxiety Disorders: This group of disorders is characterized by the presence of excessive fears, frequent somatic complaints and excessive nervousness that can interfere with functioning. Panic attack, agoraphobia, obsessive-compulsive and posttraumatic stress disorders are some of the major

sub-categories of anxiety disorders.

Adjustment Disorders: The essential feature of these disorders are the development of clinically significant emotional or behavioral symptoms in response to an identifiable psychosocial stresser(s). The clinical significance of the reaction is indicated by either marked distress that is beyond that which is expected or by impairment in social or occupations functioning. Sub categories of adjustment disorder include adjustment disorder with depressed mood, the anxiety, and disturbance of conduct and with mixed disturbance or emotions and conduct.

Other psychiatric disorders include: somatoform disorders, dissociative disorders, sexual and gender identity disorders, sleep disorders, substance abuse related disorders, impulse control disorders, dementia disorders, dissociative disorders and disorders usually first diagnosed in infancy, childhood or adolescence.

Persons with dual diagnosis can be found at all levels of developmental disability (mild, moderate, severe, profound). Estimates of the frequency of dual diagnosis vary widely; however, many professionals have adopted the estimate that 20-30% of all persons with a developmental disability also have a psychiatric disorder. The full range of psychiatric diagnoses that exist in the general population can also co-exist in persons who have a developmental disability.

Information on Dual Diagnosis

What issues does a dual diagnosis present?
The presence of behavioral and emotional problems may greatly reduce the quality of life for persons with a developmental disability. Educational or vocational progress may be delayed, residential placements interrupted, and family and peer relationships disrupted. It is imperative, therefore, that accurate diagnosis and appropriate treatment are obtained.

Why so prevalent?
Negative social conditions throughout the life span of persons with a developmental disability create enormous stress, as does rejection by others, stigmatization and lack of acceptance in general. Additionally, limited coping skills associated with language difficulty, inadequate social supports, and a high frequency of central nervous system impairment, contribute to the development of emotional problems.

What Treatments are Available?
Treatment requires a comprehensive plan with components appropriate for each person. An interdisciplinary evaluation of the individual is necessary to obtain an accurate diagnosis and to establish support and treatment needs. A thorough medical and neurological evaluation should be included to identify acute or chronic conditions that may need attention. A psychiatric evaluation may determine if medication is appropriate. Follow-up interviews are required to monitor the individual's response to the various treatments.

Psychopharmacology: Medication treatment is appropriate for many psychiatric disorders, i.e. affective disorders and psychotic disorders. Medication treatment should not be a total treatment approach per se, but rather part of a comprehensive bio-psycho-social treatment approach.

Therapy: Individual, group and/or family psychotherapy may be included in the treatment plan. Group therapies include skills training groups such as social skills, dating skills, assertiveness and anger management training. Other therapy groups may focus on specific developmental tasks such

as independence, or bereavement. The groups may be structured or unstructured, time limited or ongoing. Verbal psychotherapies may be appropriate for persons with metal retardation.

Behavioral Supports: Positive behavior support plans are developed to systemically address behavioral support needs and to teach adaptive skills. Systematic behavior supports may be implemented, in conjunction with medication therapy or other psychiatric treatments, to further assist the person in coping with their mental illness. The person who is dually diagnosed should participate in the design of the behavioral support.

Day Treatment: Day treatment programs, consisting of psycho social activities for persons who are dually diagnosed have been established in some communities. The programs serve individuals with mental retardation who have difficulty functioning in traditional school or vocational programs due to behavioral or psychiatric problems. Day treatment programs are generally designed for both rehabilitation and education, and include small group activities that focus on independent living skills, interpersonal skills, vocational preparation, and enrichment activities. Small group and individual psychotherapy are sometimes scheduled as part of the weekly program.

Social Skills Training: Social skills training is usually a time limited approach that helps persons to improve the quality of their life by enhancing interpersonal interactions. Individuals are taught effective and appropriate social behaviors.

Residential Services: Residential treatment programs have also been developed.   In community settings, a variety of residential options may be available, although the demand often exceeds the available supply. Community placements may include group homes, foster care for children, and supervised apartments, as well as programs that provide in-home family services and respite care.

Other services: provided to individuals with developmental disabilities and mental illness may include physical therapy, speech therapy, art therapy and occupational therapy, among others, depending on individual needs. The coordination of services is critical to the individual's success.

The above information obtained and adapted from the NADD website at www.thenadd.org

Other issues: Often, individuals with developmental disabilities have limited communication skills. Many people, including professionals, have difficulty understanding communication methods used by some people. Even with adequate communication, diagnosis of mental illness is a difficult task.

Psychotropic Medications

What are psychotropic medications?
Psychotropic medications are drugs prescribed to stabilize or improve mood, mental status or behavior. In other words, they are medications used to modify emotions or behavior. These medications are sometimes called "psychoactive medications".

Some drugs may have more than one purpose. For example, the anticonvulsant carbamazepine (Tegretol) may be used to control seizures in an individual with epilepsy, but it may also be used to reduce or alleviate mood disorders in another individual with manic-depressive illness. In the second case it is used as a psychotropic medication.

How is the medication named?
All medications have two names:

- Trade or Brand Name, which is chosen by the drug manufacturer and picked to be simple or memorable. Brand names are capitalized.

- Generic names are usually derived from the chemical structure of the drug. The generic name is always printed in lower case and used in scientific literature and reports.

How are psychotropic medications classified?
Psychotropic medications can be classified by their chemical structure, their action in the brain or their therapeutic action. Therapeutic action grouping is often the most useful. Examples of therapeutic action typing are:

<u>Antidepressant</u> medications which elevate mood in persons who have depression .

<u>Anti-anxiety</u> drugs are used to treat anxiety disorders and reduce anxiety symptoms.

<u>Mood stabilizers</u> reduce or alleviate mood disorders.

<u>Antipsychotic Drugs or "Neuroleptics"</u> are used to treat psychotic disorders such as schizophrenia and reduce psychotic symptoms such as hallucinations.

Some examples of medications classified by their action on the brain are:

<u>Stimulants</u> are used to treat attention-hyperactivity disorders.

<u>Beta Blockers</u> are used to treat forms of severe aggression.

<u>Opiate Blockers</u> affect some forms of self-injurious behavior.

What do we need to know about medications?
- Why the medication is being used, i.e., what is the mental illness or diagnosis? What are the specific behaviors or symptoms the medication is being used to address? Is it absolutely necessary to use the drug to address these behaviors or symptoms? Because persons with mental illness, developmental disability, or both, may have difficulty in communicating their needs and in being understood, a large number of persons may be over-medicated or mis-medicated.

- What is the intended effect, i.e., to relieve depression, improve sleep, reduce hallucinations? This is known as the therapeutic action or therapeutic effect.

- What are the unintended effects or side effects? These could include sleepiness, sleeplessness, nausea, dizziness, liver damage, sexual dysfunction, agitation, heart damage, increase in appetite, depression, and others.

- Is the drug compatible with other medications the person is taking? These are known as drug interaction. For example, two drugs a person is taking may have a mild effect when working alone, but cause severe problems with alertness when used together. One drug used with another drug might cancel out the effect of both medications.

Information on Psychotropic Medications

What disorders are psychotropic medications prescribed for?
Some of the disorders for which psychotropic medications are prescribed include depression, anxiety, insomnia, pain, panic attacks, phobias, eating disorders, spectrum disorders (which include autism, attention deficit disorder, attention deficit hyperactive disorder) Tourettes Syndrome and obsessive compulsive disorders.

Psychotropic medications are usually necessary for the treatment of major psychiatric disorders, such as, Schizophrenia, Bipolar Affective Disorder and Major Depression.

When should psychotropic medications be considered?
One major criterion used to determine if psychotropic medications should be considered is evidence that nonpharmacological, or Non-medication, intervention has not succeeded with the person. When selecting a psychotropic medication for this person the prescribing physician should first consider the medications that will have least detrimental affect on the person.

What are the consequences of taking psychotropic medications, both positive and negative?
Psychotropic medications have progressed tremendously during the last dozen years. There are many new medications now that have reduced the amount of inpatient care necessary for persons with mental illness. These newer medications have helped many persons return back to their homes, jobs and schools and allowed them to lead more normal lives. The positives far outweigh the negatives with the use of these new medications. Years ago, with the older types of psychotropic medications, the negatives (side effects) overshadowed the benefits. There still are side effects to be handled with the newer medications, but the total negative picture has been reduced tremendously.

What else must be considered when prescribing psychotropic medications?
Many psychotropic medications have negative side effects, adverse reactions or can be toxic to the individual. In-depth health assessments should be routinely performed to guard against the physical and mental problems psychotropic medications can cause.

Does the same psychotropic medication work for all persons with the same disorder?
Definitely not! What is an effective psychotropic medication for one individual may have no effect or a detrimental effect on another person.

What determines what psychotropic medication is used with a particular person?
A Psychiatrist or knowledgeable physician has to determine which psychotropic medication and dosage will benefit the person.

What regimen should be followed in application of these medications and the removal of these medications?
Depending on the particular medication, most of these are started at lower doses and the dosage is titrated (gradual increase or decrease) upward depending on responses by the patient and on side effects encountered by the patient. All of these medications should be given adequate time to reach a therapeutic level in the body prior to being evaluated clinically. This time period varies with individual medications such as; Paxil can be evaluated in a matter of 2 or 3 weeks for effectiveness, but you must allow 2 months for Prozac to do the same thing. When discontinuing a medication, the half-life of the medication, or half the amount of time it takes for the medication to leave the body, determines at what rate the removal should occur. Prozac can be stopped immediately and it tapers itself down in the body over a 35 day period, while Paxil must be slowly reduced in strength over a longer period of time to avoid withdrawal symptoms.

What criteria should be followed to ensure the therapeutic levels of psychotropic medications are maintained?
Once a psychotropic medication has been started and therapeutic levels have been achieved (varies for each medication and for each person), the individual is monitored to determine the effectiveness of the medication and the occurrence of any side-effects as well as changes in the frequency and severity of target symptoms. For certain medications a blood sample can be taken and blood serum levels measured to see if they are within the range of effectiveness. Depakote, lithium carbonate, carbamazepine are examples of psychotropic medications with measurable serum effectiveness levels.

When and for what reasons should a person be taken off a psychotropic medication?
This depends on the type of illness and on the specific needs of each individual person. For example, antidepressant therapy is often gradually discontinued after the first year. During the slow tapering process, if the original symptoms return, then the medication should be increased and continued. If the patient does not get a return of depression, then eventually the medication should be discontinued. This tapering process and reduction of dosage should be done slowly and the patient monitored closely so as not to place the patient in harm. In certain instances, such as blood dyscrasias with clozepine, the medication must be stopped immediately and the patient quickly started on another antipsychotic.

How and who should investigate and determine if the person is taking medications that are incompatible or ill advised?
Prescribing physicians should be able to provide this type of information and may refer you to a pharmacist specializing in psychopharmacology.

What should a person look for to indicate the medications are or are not working?
Judgement can be made by objectively measuring the target symptoms and clinical response of the person. Reports should routinely be made to the prescribing physician detailing the frequency and objective severity of the specific symptoms, the effectiveness of the medication and any side effects experienced from the medication.

What else might I, as a case manager, need to know to allow me effectively think about the use of psychotropic medications?
You should be familiar with the symptoms of the various types of mental illness. This will allow you to monitor the progress and recognize problems that may be occurring with either ineffective treatment or side effects.

You need to be familiar with a wide variety of medications, numerous side effects, and the large number of potential drug-drug, drug-herb, drug-over the counter medication, drug-alcohol and drug-food interactions. The role of the case manager is to recognize of potential problems and obtain assistance of the proper professionals and other support network members to help remedy the problem.

Psychotropic Medications and Restrictive Interventions
Because there are times when medications are used or rights are restricted because of a problematic behavior, positive behavior support plans should address the issues identified in the licensing regulation K.A.R. 30-63-23 Medications; restrictive interventions; behavioral management committee. Such as:

- The team has determined and clearly documented it is the least restrictive intervention appropriate.
- Positive supports, accommodations, and effective services are consistently present and documented.
- The person and/or Guardian has received information about risk, benefits, side effects and alternatives, and have given voluntary and documented informed consent.
- If medication or restrictive measures are being used as a behavior support, the behavioral issue is clearly defined. This includes but is not limited to how often behavior occurs, severity of the behavior, and how often the support is reviewed.

Additionally, plans need to address items identified in the KLO II (revision date: May 2001).

Support for Individuals Taking Medications for a Diagnosed Mental Illness
If an individual is diagnosed with a mental illness and prescribed medication to treat the mental illness, agencies have responsibilities outlined in K.A.R 30-63-23. Any time an individual is taking a medication for mental illness, the agency must have documentation to show that voluntary, informed consent has been obtained from the individual or their guardian, if one has been appointed. An agency will be considered within regulatory compliance when an individual is taking medication for mental illness without consent, if there is documentation that they made "reasonable attempts to get consent".

The use of psychotropic medication must be reviewed by the Behavioral Management Committee (third party review) to ensure that appropriate safeguards are in place, including:

- all other less restrictive alternatives have been explored and documented,
- positive behavioral programming is occurring in conjunction with the medication, environmental modifications and effective services are in place,
- appropriate documentation of the occurrence of the target behavior, and that
- data regarding the frequency and severity of the targeted symptoms or behaviors are shared with the individual, their guardian, their support team and the prescribing physician.

The prescribing physician must be a psychiatrist unless otherwise requested by the individual or their guardian.

An agency must not rely on medication alone to address the symptoms or causes of a mental illness.

Positive behavior supports, such as, providing opportunities for counseling, teaching problem solving or communication skills, teaching the individual to avoid situations that exacerbate the mental illness or teaching the person how to cope with symptoms of the mental illness must be implemented and included in the person-centered support plan.

Who can you contact to find out information about the medications that a person uses?
- the person's Psychiatrist
- the person's primary care physician
- a pharmacist
- the drug manufacturer
- reference books available at the library
- the internet

- the Clinical Pharmacology 2000 CD purchased from Gold Standard Multi. Media for $450.00 a year. The information is upgraded every three months to keep up with the changes in information about existing medications and present information about new medicines.

Effective Implementation and Monitoring
The following are key strategies to keep in mind as you support and advocate for people with behavioral support needs.

- To ensure that direct support staff do their jobs well, they must be given adequate information about the people they will be working with, taught how to implement needed supports, have opportunities to practice these skills and must receive feedback about their performances.

- Positive behavioral supports work best when staff are involved in data collection, interpretation and plan formulation and implementation.

- When training staff, discuss the relevant information, demonstrate the positive behavioral supports to be utilized and follow-up on the progress or problems with staff.

- Do not expect staff to do what you cannot demonstrate yourself.

- Consistent, accurate and timely data must routinely be kept.

- Everyone who has contact with the person and the problematic behavior must know about and consistently administer the program. Few behavioral supports can be effectively implemented by only one person.

- If you do not replace a problematic behavior with a carefully chosen, appropriate, effective substitute behavior, the person will assimilate another, possibly more problematic behavior.

- The selective reinforcer for the alternative behavior must immediately be presented following the use of the replacement behavior.

- The new behavior must be taught in the same context where the behavior will naturally be reinforced in the future.

- A possible result of an effective behavioral change is the increase of the behavior before it decreases. This is called extinction burst. The person with the problematic behavior seems to think the behavior is not working and he or she must yell louder, pinch harder, bang the table more aggressively for the behavior to be accepted and rewarded. This is a good sign, indicative that the behavior is ready for change. Too often when the problematic behavior accelerates, we think we the plan is not effective and we stop using it.

- If the problematic behavior is not affected by the approach in a short period of time, as determined by the team, the behavior support needs to be examined, altered and changed. Sometimes the first support plan will not work and must be revised.

- When we teach the use of alternative behaviors, any instruction or direction by the teacher must be at the cognitive and communicative level of the person who uses the problematic behavior. Tell the person with the problematic behavior what is happening and what will work behaviorally for them to achieve their goal in short, precise, comprehensible words and phrases.

Do not try to explain what is happening in long explanations. Demonstrate, by modeling, what works. Keep conversation with the person at a minimum.

- A change from a problematic behavior to an alternative appropriate behavior must be maintained. Too often when we effectively alter or change a problematic behavior we change or stop doing what works, and the behavior returns. Problematic behaviors do not go away. They are always there to be tried out in different settings with different persons and if they work the person uses them. Therefore we must address the problematic behavior in the other places where it is used.

- The problematic behavior will usually appear again, even though we have not seen it for weeks or months. Expect this to happen. Do not feel defeated. Just do what you did to change the behavior initially and it will go away again. Old behaviors never die, they just fade away because they no longer work.

- To every action there is a reaction. When you try to change an individual's behavior they may respond in unexpected ways. Be aware and ready to evaluate the response and adjust what you are doing to proceed with replacing the problematic behavior with an acceptable behavior.

- Why take data? First you need to see how many times the behavior happens. This is called a baseline. Then you consistently apply the "cure" to eliminate the behavior. You continue to take data to demonstrate how effectively the support plan works. If the behavior drops, continue. If not, the data may indicate you need to try something else.

- Often, a behavior will increase when you use an effective approach, then drop off dramatically.

- When you take data, don't just mark down each time the behavior happens. Watch, and write down what happened before the behavior occurred. These are the "antecedent events." They are the hints that tell you the behavior is about to happen, so get ready. They also suggest what the person might be reacting to that causes them to use the behavior.

- Make a list of the persons, situations and settings the behavior occurs in to further be able to describe what might "cause" the behavior.

- Behaviors, unless they are are physiologically based, happen for specific reasons. We use behavior to communicate to other people, just like we use verbalizations and sign language. Some of the reasons for using various behaviors are to communicate the following:
  ▸ to escape the situation
  ▸ to control a situation
  ▸ to gain attention
  ▸ to increase the chance of getting what you want
  ▸ to decrease the chance of getting what you do not want
  ▸ to get stimulation

- When you determine what the behavior succeeds in accomplishing for the user, only then can you determine an effective way to eliminate the behavior.

- If an individual is diagnosed with a mental illness and prescribed medications to treat the mental illness, agencies have certain responsibilities. Any time an individual is taking a medication for mental illness, the agency must have documentation to show that voluntary, informed consent

has been obtained from the individual or their guardian, if one has been appointed. An agency will be considered within regulatory compliance when an individual is taking medication for mental illness without consent, if there is documentation that they made "reasonable attempts to get consent."

- The use of psychotropic medication must be reviewed by the Behavioral Management Committee (third party review) to ensure that appropriate safeguards are in place, such as:
  - ‣ less restrictive alternatives have been explored,
  - ‣ appropriate documentation of the occurrence of the target behavior,
  - ‣ positive behavioral programming is occurring in conjunction with the medication, and that data regarding the frequency and severity of the targeted symptoms or behaviors are shared with the individual, their guardian, and their support team and prescribing physician.

- The physician prescribing medication for mental illness must be a psychiatrist unless otherwise requested by the individual or their guardian.

- An agency must not rely on medication alone to address the symptoms or causes of a mental illness. Positive behavior support programs, such as, providing opportunities for counseling, teaching problem solving, teaching the individual to avoid situations that exacerbate the mental illness or teaching the person how to cope with symptoms of the mental illness must be implemented.

Resources

Durand, V.M. (1999). Functional communication training using assistive devices: Recruiting natural communities of reinforcement. Journal of Applied Behavior Analysis, 32, 247-267.

Carr, E. G. and Durand, V.M. (1985).   Reducing behavior problems through functional communication training. Journal of Applied Behavior Analysis, 18, 111-126.

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Iwata, B.A., Dorsey, M.F., Slifer, K.J., Bauman, K.E. and Richman, G.S. (1982/94). Toward a functional analysis of self-injury. Journal of Applied Behavior Analysis, 27, 197-209.

Micheal, J. (1982). Distinguishing between discriminative and motivational functions of stimuli. Journal of the Experimental Analysis of Behavior, 37, 149-155.

Additional Resources

1. Training module: "Dual Diagnosis: Schizophrenia and Other Psychotic Disorders and Developmental Disabilities," Developed by: Kathleen Olson, PhD, Patricia A. Black, M.S., Jessica A. Hellings, M.D., Kansas University Affiliated Program, P.O. Box 738, 2601 Gabriel, Parsons, KS 67357, 620/421-6550, copyright 2001 by University of Kansas.

2. Training module: "Dual Diagnosis: Mood Disorders and Developmental Disabilities," Developed by: Kathleen Olson, PhD, Patricia A. Black, M.S., Jessica A. Hellings, M.D., Kansas University

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3. Training module: "Dual Diagnosis: Assessment," Developed by: Kathleen Olson, PhD, Patricia A. Black, M.S., Jessica A. Hellings, M.D., Kansas University Affiliated Program, P.O. Box 738, 2601 Gabriel, Parsons, KS 67357, 620/421-6550, copyright 2000 by University of Kansas.

Module 4: Support Coordination Issues

Criminal Justice System Involvement

Prevention/Risk Assessment

The single most important approach to supporting someone regarding criminal system issues is prevention. The second most important is getting the person assistance as early as possible if he/she becomes involved with being accused of criminal activity.

- The case manager should consider each person he/she supports. Is there any issue in their life–a life pattern, a challenging behavioral support need, a mental health issue, a domestic situation, a substance abuse, or otherwise–that may lead them into involvement with the criminal justice system? If so, the issue should be addressed head on; a risk assessment should be conducted to explore options; and appropriate supports/responses should be spelled out in the persons' support plan, with follow up monitoring to ensure implementation.

- The case manager should be particularly vigilant about issues of challenging behavior. It is not an acceptable practice for staff to utilize law enforcement in response to a behavioral support need. It is not appropriate for staff, family members, or others to "teach a lesson", "impose consequences," "let him sit in jail a night and see what it's like," or similarly respond to behavioral support needs. The case manager's role in these situations is to help the person and his/her supporters to be proactive in recognizing, responding to and preventing escalation of the person's behavioral support needs. And as such, those efforts need to be in accordance with least restrictive intervention standards in K.A.R. 30-63-23.

- If a person gets involved with the criminal justice system as a result of a behavioral support need going unmet, it is our service system that needs to be accountable – not the person alone. And it is our service system, under the advocacy of the person's case manager, that should actively address and remedy the situation (including explaining to criminal justice officials what went wrong, who is/is not responsible, and how future occurrences will be avoided).

- Similarly, if the person unexpectedly has criminal justice system involvement, or develops a life issue, which may lead to such involvement, the case manager should promptly address the issue – in collaboration with the person and support network -- with appropriate risk assessment and updating of the person's support plan.

Pre-charge Advocacy: Person's Rights

If a person gets involved with the criminal justice system, he/she is entitled to core civil rights and due process, which the case manager must guard. This includes all the basic rights any of us would have in that situation – including the "TV" stuff: the right to remain silent, to understand that your comments will certainly be used against you, and the right to an attorney (you do not have to answer any questions, other than your identity, without an attorney – and you must say you do not want to answer questions without an attorney).

As a case manager, you must be vigilant about ensuring that the person understands and has full opportunity to exercise these rights. Getting "questioned" as a potential suspect and/or arrested by the police is serious business. At this point the case manager is NOT responsible for:

- Doing a generic public duty for the police, for any potential victim, for the person's family, and so on.
- Telling investigators about the person's history, other similar events, past law enforcement involvement, etc.
- Bringing the person in for questioning.

At this point, the case manager IS responsible for:

- Ensuring that the person understands what is going on and what his/her rights and options are.
- Helping the person get an attorney and helping the person communicate with the attorney so that he/she understands what is happening and what his/her rights and options are.
- Ensuring that the person's needs – which may change as a result of a potentially traumatic event – are identified and met (including increased supervision, mental health supports, etc.).
- Keeping the person informed and involved in decision making.

Where and When to Go For Help
If someone you support becomes involved as a suspected offender, or is charged with a crime, the general rule is that he/she should get assistance of an attorney as quickly as feasible. In criminal matters, there are basically two options for legal representation:

Public defender: If the person is unable to afford a private attorney, and has been formally charged with a crime which could result in incarceration, the Court will appoint a public defender to provide legal representation. However, this option would generally not provide the person with legal advice and assistance during the time period prior to the criminal charge actually being filed (such as during the law enforcement investigation stage).

Private attorneys: A private attorney, particularly someone with experience in criminal matters, would be a valuable resource for anyone who has or may become involved as an alleged offender in the criminal justice system. Of course, the expense of a private attorney would have to be a factor for the person to consider.

When helping the person gather information about private attorneys, local dynamics and experiences are important. In addition to attorneys that you or your colleagues may know, or the person you are helping and his supporters may know, you can talk to attorneys for suggestions (such as the attorney for your agency, attorney members of the Board of Directors, etc.). Your local yellow pages may at least be a starting point for people who advertise as practicing the type of law you are seeking assistance with. Another resource that may be helpful is the statewide Lawyer Referral Service (sponsored by the Kansas Bar Association), which can be reached at (800) 928-3111. Keep in mind that this will get you information about attorneys in your geographical area, and about their primary areas of practice (such as criminal defense work), whose customary fee is $100 or more an hour, and who by payment of membership fee and good standing with the Kansas Bar are part of this referral system. You can get the basic information about attorneys in your area, and then contact the attorney directly.

- When assessing the ability of someone you support to pay for an attorney, you should discuss with them the long-term impact of that decision. Also, explore payment options (many attorneys will take "installment"-type payments over time for their services), as well as alternative fund access (such as a special needs fund of the person's service provider and/or CDDO) – even on a temporary, limited basis such as during the investigative stage.

- Again, consider these issues proactively. If the person has a history of criminal justice system involvement and/or is particularly vulnerable to it, consider the option of developing a relationship with an attorney who can get to know the person and his/her circumstances so that you do not have to build this relationship in a crisis circumstance.

Alternatives to Incarceration

<u>Making it Right</u>

Sometimes our service system drops the ball and exposes someone to criminal prosecution. It doesn't mean that someone has done something awful and/or that there will be any negative consequences for the service provider. It could be anything from someone not receiving or following training about behavioral supports or crisis-type responses (and calling the police in response to behavior that could have been avoided and/or supported as part of the person's services); responses used not working in a particular situation and alternatives not thought of or implemented; someone not showing up on time, so the person gets in over his head and engages in potentially criminal behavior. All of these things have happened and just need to be managed.

The important part is that the person getting supports should not have to bear the burden of a criminal prosecution in these types of situations. Instead, as a case manager, you should help the person advocate for a resolution that involves clearly describing the type of support that is and

should have been available for the person; taking responsibility for the role that a service gap played in the behavior leading to a criminal charge; and assuring - with specific plans that can be and are implemented - the law enforcement entity (police, prosecutor, or otherwise) of improved supports that will prevent a repeat of the situation.

Remember that - as law enforcement officials - a key interest for people in that role will be public safety. As a general rule, a reasonable accounting of the circumstances, a sharing of the responsibility for improvement, an explanation of how mis-steps occurred and will be prevented, and a request that the criminal matter not be pursued can go a long way toward resolving these unfortunate incidents. **The sooner this can happen, the better**.

Diversion

This is a formal agreement between the defendant (the person being charged with a crime) and the prosecutor, that requires the defendant to complete some specific things and causes the case to be put "on hold" during the time of the diversion agreement process.

- Typically, the diversion agreement attempts to address the underlying problem (such as counseling for anger or domestic violence, or payment of fees for a bad check charge, or treatment of a substance abuse).
- Generally you must stipulate to (agree that you engaged in) the key facts of the charge, and effectively waive a trial – that is, you will no longer be able to contest the facts as alleged against you. So, if you do not successfully complete the diversion agreement, you go back to the status of being charged with the crime, but not being able to contest the facts you previously agreed to.
- The agreement includes time-limited provisions that, if successfully completed, result in the charge being dismissed and you not having a conviction record (except in the case of DUI).
- This may be a good option for someone who has a first time offense that involves activity that he/she actually engaged in; and who can get assistance or additional supports needed to prevent recurrence. In any event, you should help the person consider this option with his attorney.

Individual Justice Plans

Individual Justice Plans offer an alternative to typical resolution of pending/existing criminal charges, and can be a supplement to person centered planning. If the person you support is interested in pursuing this alternative, as the case manager you should advocate with the person's attorney and the Court to consider this as a resolution to the charge.

The following information is taken from a presentation of Kansas Advocacy & Protective Services, Inc. - for additional information and/or for training materials, contact them at 1.877.776.1541

"Individual Justice Plans: Alternatives to Incarceration" Presented by Kansas Advocacy & Protective Services, Inc.

Kansas Advocacy & Protective Services, Inc. encourages service providers, the legal community, and anyone interested in the criminal justice system to consider this alternative way of working with criminal offenders with disabilities.

WHAT IS AN IJP?

- The Individual Justice Plan (IJP) is an interagency approach to issues that arise when an individual with mental retardation or mental illness has contact with the criminal justice system.
- The IJP's primary goal is to prevent incarceration of individuals with mental retardation or mental illness by giving them support services in the community. This helps individuals with mental retardation or mental illness get proper services and reduces the possibility of re-incarceration.
- IJPs are conceptually similar to the Individual Education Plans (IEPs) used in schools and the Individual Program Plans (IPPs) or Individual Service Plans (ISPs) used at community developmental disabilities organizations (CDDO) and their affiliates

WHAT ARE THE BENEFITS OF AN IJP?

- IJPs are a proactive approach that discourage further involvement in the criminal justice system.
- IJPs help individuals with disabilities get the services they need and promote self-empowerment.
- IJPs provide for early identification of the offender's potential noncompliance with probation and parole plans.
- IJPs promote safety in the community since the services help monitor the offender's behavior and if the offender does not comply with the IJP, the inter-agency team immediately notifies the probation or parole officer.

WHO DEVELOPS AN IJP?

- The criminal justice and human services systems are responsible for developing and carrying out the IJP.
- Generally, the lower the individual's functioning level and the lower the risk, the more likely that the human services system will have the primary responsibility
- The higher the individual's functioning level and the greater the risk, the more likely that the criminal justice system will have primary responsibility.
- Where there is intermediate risk and severity of the offense, the criminal justice and human service system may share responsibility equally. The IJP is most appropriate where public safety does not require incarceration.

WHO DEVELOPS AN IJP?

- All agencies involved in the IJP must work together. Agencies need to clarify philosophical differences.
- A primary goal of the criminal justice system is to ensure that the individual does not commit more crimes.
- A primary goal of the human services system is to increase the individual's independence.
- The agencies must be aware of and discuss philosophical differences to avoid misunderstandings.

HOW DOES AN IJP WORK?

Needs Assessment:
First, a service provider or other interested person must help the offender identify services needed for community living.

- Residential
- Education
- Medical, psychiatric
- Advocacy
- Social
- Vocational
- Financial, family
- Transportation
- Psychological
- Recreational

After completing the needs assessment, the local agencies involved in the offender's rehabilitation should meet to decide what services they can provide. Involved agencies may include:
- The local community mental health center
- The local CDDO or an affiliate
- Vocational Rehabilitation Services Office
- An Independent Living Center
- SRS Adult Protective Services
- Income Support and Medical Services
- Court Services
- School system participants
- And the Probation or Parole Office involved in the person's case

An inter-agency team should also consider involving the offender's:
- Employer
- Family
- Clergy
- Friends

Choose a Team Leader:
One agency participant should be designated to lead the inter-agency team. The leader should:
- Chair the meetings
- Delegate responsibilities
- Write down the team's decisions
- Be the point of contact

This person is contacted if the offender does not follow the plan or if a service provider cannot carry out part of the plan.

Since the probation and parole officer has legal authority to supervise the offender, he or she is often the team leader.

If the offender misses appointments or may not be fully complying with the plan, a team member could tell the probation and parole officer. The officer can deal with the problem before it becomes a probation or parole violation.

<u>Written Agreement</u>
Once the inter-agency team assembles, the members, including the offender, will decide how to carry out the plan. The team must decide:
- Who will do each task
- When the tasks will be completed
- How will each task be accomplished

Team members must not assume anything. For example, saying that the offender will contact an agency on a certain date can cause problems for an individual who does not have transportation or a telephone.

Team members must specify how the offender will make contacts with the agencies.

Some offenders do not understand the importance of attending scheduled meetings, so the team must be prepared to repeatedly stress the importance of following through on obligations and to develop contingency plans.

The team must cover the offender's needs thoroughly, write the plan down, and send the plan to each agency or service provider working with the offender, with appropriate authorization. The format of the plan does not have an established or required style; it should be consistent with and include the elements of a Person Centered Support Plan. Remember that there will be people involved in this process not accustomed to our service system, so keep the language clear.

<u>Modification</u>
Because the offender's needs may change during the IJP process and the participation of agencies may change, the plan needs to be flexible.Often after the plan is in place, the inter-agency team may identify new needs and the offender's initial needs may change. Therefore, the agencies providing services for the offender must talk after the plan is in effect. Additional inter-agency meetings may be necessary to review problems with the plan or the offender's compliance

<u>Where Do I Get More Information?</u>
Kansas Advocacy & Protective Services, Inc.
3745 S.W. Wanamaker Rd.
Topeka, Kansas 66610
1.877.776.1541 (voice/TDD, toll-free)
1.785.273.9414 (fax)
www.ksadv.org

Questions of Competency to Stand Trial

When a person with cognitive disabilities gets involved in the criminal justice system, the question may arise as to whether the person is "competent." This means: 1.) Does the person understand the nature of the proceeding (who are the police/prosecutors; who are his representatives; who is the judge – and what are their roles; what is he accused of doing and what might happen if he is found guilty); and 2.) Is the person able to assist in his defense (such as, can he help his attorney know what happened involving the event, or that he was not involved)?

If there is a question about that competency, someone involved in the proceeding needs to raise the issue with the Court and the person will need to be evaluated.

As a case manager, your role is to ensure that the person has legal assistance, and that if there is a question about competency you bring that to the attention of the person's attorney and/or the Court. You should discuss with the person's attorney what the impact of the competency issue would be for the person. In addition, you should assist the person in providing relevant documentation (such as previous evaluations) that may be useful in the evaluation process (again, in concert with his attorney if available).

Authority to Court-Order Placement

There is no formal authority for court-ordered placement in community-based services, ICFs/MR and/or state hospitals for people with mental retardation. While a person may be appropriately ordered to apply for services, cooperate in the application process, attend to a competency evaluation, or such limited matters, as a case manager, you should know and advocate for the person's interests if this situation arises and a court attempts to "order" the person to one of those settings for services.

If it is in the best interest of the person – such as being an agreed resolution that will avoid more punitive or negative outcomes – it may be appropriate for the person and the case manager to work toward accessing receiving services. The agreement could not mandate permanent or involuntary presence of the person in a setting. Also, the same eligibility and access standards applicable to others seeking services would apply to the person, and a court order for services would not assure either eligibility or service access. The person and the case manager would need to work with the CDDO involved to access services.

Monitoring Through Incarceration & Release

If someone you support gets incarcerated, you should continue to have contact with him/her to ensure that needed services are available and accessed upon release.

Even though this activity is not "billable" when the person is actually incarcerated, minimal effort to keep track of the person - and to be prepared to meet his/her needs upon release - should be considered as a professional obligation and will be beneficial to all concerned in the long term.

Guardianship & Other Alternative Decision Making

Overview of Guardianship

Guardians are a support for people who meet this definition of "disabled person": "any adult person whose ability to receive and evaluate information effectively, or to communicate decisions, or both, is impaired to such an extent that the person lacks the capacity to manage such person's financial resources, or to meet essential requirements for such person's physical health or safety, or both."

A person who has a guardian is known as a "ward," defined as: A person who is found unable, through a decision of the court, to manage the basic requirements for physical health or safety.

Who May Serve as Guardian?
- Suitable individual or corporation to serve as guardian or conservator or both. KSA 59-3013.
- More than one individual or corporation may be appointed guardians for one ward KSA 59-3013.

Procedure to Appoint Guardian
(Petition: KSA 59-3009)
- Name person needing guardianship
- List reasons for needing guardianship
- Names of family members
- List of property
- List names of persons who could witness necessity of Guardianship

Notices
(Notices given by the court to those involved in the hearing)
- Ward/conservatee
- Attorney of the proposed ward/conservatee
- Any person court believes appropriate
- Notice must be personally served on the proposed ward/conservatee and his/her attorney not less than five days prior to hearing date KSA 59-3010

Hearing
- Held before a judge or 6 person jury if so requested by proposed ward in writing
- All evidence to be presented and court or jury decides if Guardianship is necessary.
- Hearing conducted in informal manner, in a physical setting not likely to have a harmful effect on the proposed ward/conservatee.

Appointment
- Not shown to be disabled
  - ▸ Case dismissed

- Shown Disabled
  - ▸ Letters of guardianship issued
  - ▸ File written oath of guardianship
  - ▸ If conservator filing of a bond in such an amount as directed by the court

Guardianship
- Full or Plenary:
  - ‣ Appointed and "shall be possessed of all powers & duties of a guardian"
  - ‣ "Limited" will not appear on the letters of guardianship
- Limited: KSA 59-3018, 3014
  - ‣ Court determines to what extent the disabled person is able to:
    - Ƨ Make decisions, which affect him/her
    - Ƨ Which of the powers and duties the guardian shall be assigned
    - Ƨ The above are specified in the "Letters of Limited Guardianship"

Duties, Powers of Guardians
- Guardian - report on ward's welfare KSA 59-3018 (annual written report filed with the Court that created the guardianship)
  - ‣ Assure the personal, civil and human rights of ward are protected
  - ‣ Take charge of the ward by providing:
    - Ƨ Care
    - Ƨ Habilitation
    - Ƨ Support
    - Ƨ Treatment
    - Ƨ Education
    - Ƨ Maintenance

The law makes it clear that the guardian is not obligated to use the guardian's own financial resources for support of the ward.

Limitations on Guardians Powers
- The guardian cannot:
  - ‣ Place ward in facility without court order, giving permission for the requested placement.
  - ‣ Consent on behalf of ward, to psychotherapy without court order unless an emergency
  - ‣ Consent on behalf of ward to withholding of lifesaving medical procedures
  - ‣ Consent on behalf of ward to the performance of experimental biomedical or behavioral procedure or participation in biomedical or behavioral experiment unless certain statutory conditions are met
  - ‣ Prohibit marriage or divorce of ward
  - ‣ Consent on behalf of ward to terminate ward's parental rights
  - ‣ Consent on behalf of ward to sterilization of ward without court order

Related practice tips for case managers: It is important that you have documentation that demonstrates the creation of guardianship. The court document that creates the guardianship also describes the powers of the guardian, as well as any limitations on the relationship in each situation. In addition, even when a guardianship is present, it is important that you support the person you serve in having as much input as is feasible and appropriate in each situation. When decisions are being made, the values and preferences of the person should be taken into the account and helping supports – including guardians – in making decisions and explaining those decisions to the person.

Sometimes questions arise as to the guardian's authority to restrict the ward from visiting with or associating with others. For example, the guardian may think that a person is a negative influence for the ward. In assessing this type of situation, the substantive issues to consider are that: (a) the guardian is responsible to "assure the personal, civil and human rights" of the ward are protected – which includes core personal right of association; and (b) the guardian is specifically not allowed to prohibit marriage or divorce of the ward (which are intense forms of association issues). Thus, it is unlikely that it would be appropriate for a guardian to "prohibit" the ward from having friendships or associations.

If this situation arises for someone you support, it is important to help the person and his guardian work through the related issues, explore the values/concerns/fears/desired outcomes involved for each, attempt to arrive at an agreement about how to manage the situation (with the opportunity to assess progress and make changes over time), get the assistance of a facilitator or mediator if needed, and - if informal resolution is not possible - seek assistance from the court that created the guardianship in further specifying the authority or limitations of the guardian.

Of course, if the relationship is causing a risk of harm for the ward, the person (or the guardian) could address that through directing that the harmful person not come back, reporting the person to the police as a trespasser and/or obtaining a court order prohibiting the person from being there.

Conservators
A person who has a conservator is known as a conservatee, defined as: A person who is found unable, through a decision of the court, to obtain, administer and dispose of real and personal property, intangible property, business property, benefits and income.

- This is a more formalized relationship, and provides the conservator with control over all funds belonging to the person – regardless of source. It is also an alternative to guardianship, in that the conservator has no decision-making power involving other issues in the person's life.
- The conservator is required to formally report to the court, annually, about the management of the conservatee's funds. That report is public information, which can and should be shared with the person.
- The case manager should help the person to understand the role of the conservator and to assure that safeguards are in place so that the person gets information about how his/her funds are being utilized.

Duties, Powers of Conservators
- Annual accounting of financial resources KSA 59-3019
- Specific duties: KSA 59-3019-3026, 3029-3031
- Pay debts; sells assets when in best interest, protect and defend conservatee, manage business, invest funds as appropriate
- Merge securities
- Lease real estate for up to 3 years, subject to court approval, to meet best interests of the conservatee.

- Lease real estate more than 3 years, after specific petition to and approval by the court, to provide for the support, maintenance and education of the conservatee/spouse/children or to pay the conservatee's debts.
- Sell real estate
- Extend mortgage

Alternatives to Guardianship

- As the person's case manager, you should recognize that guardianship is a substantial restriction on the person's individual rights. Therefore, you should assist the person to understand those restrictions, and available alternatives to them. Explore with the person what his or her personal needs are which can be supported by the guardianship relationship; what that relationship means to him/her; what he/she thinks about the level of restriction or intrusion in his/her life; and what the range of those support options are (from nothing to payee, powers of attorney, conservator, limited guardianship or full guardianship – in that order of intensity).

- For some people, guardianship may be an acceptable and appropriate relationship that signals security or comfort; for others, it may be an intrusion that makes them feel stripped of their adulthood or otherwise uncomfortable. It is a personal decision, which you should help the person understand, weigh and make informed decisions about – and then help the person advocate for their decisions.

Limited Guardianship

- The case manager should assist the person to understand that the support of a guardian can be limited to specific issues of his or her life (such as medical decisions or other service decisions). The specific role of the guardian can be described in the letters of guardianship (the formal court order creating that relationship). If specific limitations are important to the person, this will be a useful way to get them in place.

- If limitations are not specified in the order establishing the guardianship (sometimes called "Limited Letters of Guardianship"), the limitations are not in place and enforceable. If the person believes that limitations are or become appropriate in the guardianship relationship, the case manager should assist the person to understand this option and access legal assistance to formally address the limitations.

Representative Payee

- This is a good alternative to guardianship, if the primary support the person needs is help in managing governmental benefits (SSI income).
- The payee does not have control or authority about other decisions in the person's life, or about funds that are non-governmental (work income, etc.). However, other income sources may impact the amount and availability of governmental benefits, or vice versa, and the Payee should be worked with collaboratively to understand and manage the impact.

- Case managers should assist the person in understanding the payee's role, and in assuring that there are safeguards in practice, which avoid "conflict of interest"-type concerns (such as the person's only service provider also serving as payee). In such cases, safeguards may include that there is regular and detailed accounting to the person about the use of funds.

Power of Attorney
Excerpted from "A Guide to the Legal Rights of Kansans With Disabilities," a publication of the Kansas Advocacy and Protective Services

- A regular power of attorney is a written document in which one person (the principal) authorizes another person (the agent) to act on his or her behalf in financial matters. The purpose of a power of attorney is to prove to a third person or organization that the agent has the authority to act for the principal. An individual who gives a power of attorney to another individual must have legal capacity to do so; accordingly, minors and adult individuals who are adjudicated "disabled persons" (within the definition for guardianship purposes) cannot give a power of attorney to an agent. The principal can revoke the power of attorney if he or she no longer wants an agent or if the agent dissatisfies him or her. Usually powers of attorney end if the principal dies or if the principal revokes the agency. It is important to recognize that regular powers of attorney become void if the principal becomes legally incapacitated or is adjudicated a "disabled person."

- Durable powers of attorney are a special type of power of attorney that do not become void because of the principal's incapacity. The Kansas Uniform Durable Power of Attorney Act requires that a durable power of attorney include the statement "this power of attorney shall not be affected by subsequent disability or incapacity of the principal," or "this power of attorney shall become effective upon the disability or incapacity of the principal," or a similar phrase showing that the principal wants the power of attorney to be effective even if the principal becomes incapacitated. The durable power of attorney is a simple document for an attorney to draft and can cover any situation in which the agent acts for the principal – contracting with third persons, buying and selling property, paying bills, filing tax returns, or whatever. A durable power of attorney can be an appropriate method of an individual to give a trusted friend or relative authority to handle certain financial affairs; the agent's powers are limited to those specified in the durable power of attorney.

- The durable power of attorney for health care decisions is a special type of durable power of attorney that allows a principal to appoint an agent for medical and health care decisions. The law creating durable powers of attorney for health care decisions assumes that individuals have the right to plan and name a particular person to act for them if they become so incapacitated that they cannot make decisions about their health care; individuals can tell their agents what actions they want taken. Durable powers of attorney for health care decisions extend individuals' decision making capacity into the future, through their instructions to a trusted person whom they can rely upon to act as they would act if still able to make their own choices about health care. An agent cannot be the treating health care provider, an employee of the health care provider, nor an employee, owner, director or officer of a health care facility unless the agent and principal are closely related.

An individual signing a durable power of attorney for health care decisions may give the agent authority to take certain actions for the principal, according to the principal's instructions:

- To consent, refuse consent, or withdraw consent for health care decisions
- To make decisions about organ donations and autopsies,
- To arrange for the principal's admission to a hospital, psychiatric facility, hospice, nursing home, or other medical facility,
- To employ or discharge health care personnel, including physicians, psychiatrists, psychologists, dentists, nurses, therapists, and
- To have access to the principal's medical and hospital records.

The agent does not have authority to take certain actions for the principal:

- To take any action not provided for in the durable power of attorney for health care decisions,
- To revoke an existing living will,
- To take action or make decisions until the principal becomes disabled or incapacitated, as determined by the principal's physician, unless the durable power of attorney for health care specifically provides otherwise, and
- To take any action inconsistent with the principal's expressed wishes.

The act creating durable powers of attorney for health care decisions includes a model form; an individual's document needs to be substantially in that form. (See K.S.A. 59-632.) An individual can add other specific instructions for the agent or designate an alternative agent if, for some reason the original agent becomes unable to act. Remember that the principal must comply with all statutory requirements regarding signing and dating the power of attorney.

How to Access Guardianship/Conservatorship

There are two basic ways to access a guardian/conservator:

- **Privately.** This means that someone files a civil guardianship and/or conservatorship action directly with the court, using his or her own attorney. Automatically, an attorney is designated by the court to represent the person directly for whom guardianship is sought (this person is referred to as a Guardian Ad Litem, and is responsible to look out only for the interests of the proposed ward).

  The person bringing this action may be a family member; friend or interested party who thinks that guardianship is in the best interest of the proposed ward. That person is responsible for the costs and fees associated with the filing of the action (including filing fees, attorney's fees, etc.), and does not get reimbursed for his/her service as a guardian.

- **Publicly.** The Kansas Guardianship Program (3248 Kimball Avenue, Manhattan, Kansas, 66503; phone 800/672-0086; fax 785/587-9626) is involved in these actions. Typically, through a contract with SRS, the Kansas Guardianship Program is involved and pursues guardianships for people who are referred to them through SRS, Adult Protective Services (APS). For

example, if a person has been subject to abuse, neglect or exploitation, and/or has been unable to protect himself from negative situations, one responsive support from APS may be to suggest that he get a guardian to help prevent similar situations in the future. APS gets involved in assessing and recommending guardianship or conservatorship only for persons who are involved in a case of reported abuse, neglect or exploitation.

These actions are brought and funded through the SRS Legal staff, and it is their decision as to which cases get pursued. Matters are referred to SRS Legal staff through SRS Adult Protective Services. The Kansas Guardianship Program (KGP) does not separately pursue guardianship actions for people privately. The KGP recruits and manages volunteers to serve as guardians. The volunteer guardian, once approved by KGP and appointed as someone's guardian by the court, gets a small fee to offset expenses associated with the guardianship work ($20 per month). KGP is also available for training and information about basic guardianship duties. It is not appropriate or effective to contact either SRS Legal or KGP for pursuit of guardianship in routine situations where the person could generally benefit from that type of support, absent situations involving reported abuse, neglect or exploitation. Exploring the option of private guardianship actions (as described above) are the appropriate avenue in routine situations.

The case manager's role when a guardianship action is filed is to continue to educate the person about the action, the impact and the options; and to advocate for the person's interests once that education has occurred. If the person is opposed to guardianship – or wants to have limitations placed on the guardianship – the case manager should work closely with the Guardian Ad Litem and even attend court hearings to ensure that the person's interests are expressed.

Similarly, if the person is in need of guardianship support, and would benefit in his/her life by that type of support, the case manager should (after education and option exploring) assist the person in identifying and recruiting someone to serve as a guardian. This help should not await something negative happening in the person's life.

Not a Magic Bullet

It is important for case managers to recognize that there is no "magic bullet" in the guardianship role. The guardian, for example, cannot direct away troubling behavior patterns, stop sexual contact, eliminate substance abuse, remedy mental illness, and so on. A guardian may be of some assistance in helping the person to recognize and address these types of issues, but "clamping down" and "restricting" people through the use of a guardian does not equate to effective behavioral and other supports. It is unfair and ineffective to expect that a guardian will be able to remedy these types of intensely personal and complex issues.

If a guardian is present (or sought) in the life of someone with these types of support needs, the case manager should:

- Remember that the primary interest remains with supporting the person and advocating for his/her needs and preferences. Also, remember those key civil liberties that the guardian cannot restrict.
- Work with the guardian to become very knowledgeable about and effectively involved with the person – on a personal level where these issues occur – so that the guardian can be a valuable resource and member of the person's support network.

DNR/End of Life Issues

Occassionally, someone you support faces issues that raise end of life decisions – such as a terminal illness or other medical condition. Sometimes the person you support or their guardian or parent even present a "DNR" (do not resuscitate) directive. It is important that you consider the circumstances broadly, and that service provider staff not be automatically responsive to such DNR directives. Some issues to consider in this subject area are:

- One of the specific limitations on the power of a guardian, set out in K.S.A. 59-3018(g)(4) is that the guardian cannot "consent on behalf of the ward to the withholding of life-saving medical procedures, except in accordance with the provisions of K.S.A. 65-28,101 through 65-28,109".

- That exception involves what is called the "Natural Death Act," which relates to medical procedures that serve only to prolong the dying process, involves decisions made between the person and his/her attending physician, and provides immunity from civil or criminal liability for any "physician, licensed health care professional, medical care facility or employee thereof who in good faith and pursuant to reasonable medical standards causes or participates in the withholding or withdrawing of life-sustaining procedures from a qualified patient pursuant to a declaration made in accordance with this act." (K.S.A. 65-28,106)

- A "DNR" directive, as defined in K.S.A. 65-4941, involves specific decisions about specific medical care, and provides immunity from liability for health care providers. The immunity language at K.S.A. 65-4944 is as follows: "No health care provider who in good faith causes or participates in the withholding or withdrawing of cardiopulmonary resuscitation pursuant to a 'do not resuscitate ' order or directive or the presence of a DNR identifier shall be subject to any civil liability nor shall such health care provider be guilty of a crime or an act of unprofessional conduct."

- Direct service professionals providing support to people with developmental disabilities under the regulatory standards for such services in Kansas are not health care providers with that protection. Such services are governed, in part, by the language in K.A.R. 30-63-26 (d), which requires that staff who have been certified by a recognized training agency to give CPR and first aid be available whenever people are receiving services. Direct service professionals are required to have and utilize appropriate first aid/CPR training – which, on occasions, will dictate certain types of emergency responses. For example, if a person being served has a specific medical condition, which would cause increased danger if chest compressions are utilized as part of an emergency response, alternative first aid/CPR responses would be necessary. Direct service professionals cannot, however, automatically honor DNR directives – regardless of who

creates or presents them. The response to such directives should be that the direct service staff utilize appropriate first aid/CPR responses, and then hand over the DNR directives to health care providers involved in the situation.

- So, what do you do in these difficult situations?
    - ▸ Explore available resources to support the person and his/her supporters, including provider nurses, natural supports, and Hospice services.
    - ▸ Help the people involved in the situation know and honor the ground rules.
    - ▸ Anticipate and plan – meet these issues head on. It is essential – for the person's interest, for the comfort and protection of support staff, for the peace of mind of the person and family – that no one be put in a situation of facing end of life decisions without a clear understanding of what steps he/she should take.

Changing Guardians

Sometimes situations arise that necessitate considering a change in guardians. This is a significant decision, not to be made lightly, and it requires court approval – however, it is a feasible option if and when needful. Examples of this would be:

- An acute disagreement between the person and his/her guardian about an important life matter. This may be a medical condition and related treatment options; most appropriate service environment; the use of restrictive service practices or psychotropic medications.
- Instances of the guardian not hearing out and being responsive to the person's opinions or preferences on core life issues.
- Inability or unwillingness of the guardian to participate in the person's life (planning for supports, providing important consents, etc.)
- Illness or aging concerns.
- Resignation of the guardian
- Court determination that the guardian has not been fulfilling his/her duties or has caused negative outcomes in the person's life.

The case manager's role if a person wants to seek a change of guardianship is to continue to educate the person about the action, the impact and the options; and to advocate for the person's interests once that education has occurred. The case manager should work closely with the person's attorney and even attend court hearings to ensure that the person' s interests are expressed.

Restoration

- If the person believes that he/she does not need the support of a guardian, the case manager should help to explore the option of restoration.
- This is a formal proceeding within the context of the guardianship court case, and involves formally requesting the court to reconsider the previous order establishing guardianship. It will involve a court hearing before the judge, and presentation of evidence that the person – for whatever personal reasons and/or changes in his or her life – no longer needs the support of a guardian.

- As such, careful education for the person, full consideration of the options, and legal assistance will be needed. After considering this option, if the person wants to pursue it, the case manager should assist him/her in getting access to an attorney for consultation and, if appropriate, representation in a restoration proceeding.
- This process involves petitioning the court that established the guardianship. The person needs to obtain his or her own attorney for this process (that is, one is not automatically appointed by the court for this purpose). A hearing will be conducted, and if it is not shown by clear and convincing evidence that the person continues to be disabled, the ward will be restored to capacity.
- The court has discretion to wait to hear a petition for restoration of capacity until six months after the guardian has been appointed.
- A ward can repeatedly petition for the court to consider restoration (that is, a person is not limited to asking for this change only one time).

If someone needs help with presenting a request for restoration, in addition to obtaining a private attorney, a potential resource for the person to consult with is Kansas Advocacy and Protective Services (phone: 877/776-1541). One of their priority activities is assisting people to consider the option of restoration (including through investigation of the facts and explanation of the legal standards) and, in some cases, provide legal representation to the person in that process.

Resources:
Kansas Guardianship Program (800/672-0086): training materials/information about guardianship.
Kansas Advocacy & Protective Services (877/776-1541): training, materials and information about guardianship; assistance with restoration proceedings.

Accessing/Continuing Benefits – General Medicaid Services

What is Medicaid?
Title XIX of the Social Security Act, known as Medicaid, is an entitlement program, which is designed to help states meet the costs of necessary health care for low-income and medically needy populations. Medicaid is available only to members of low-income families with children and pregnant women, and to persons who are aged. Individuals may also become eligible for Medicaid if they "spend down" sufficient income on health care to quality for Medicaid. For eligible groups, Medicaid creates three distinct sets of legally enforceable guarantees: 1) entitlement to health insurance; 2) entitlement to Federal financial assistance; and 3) entitlement to free choice of provider.

Note: Medicaid is the payer of last resort. All other insurance options, public or private, must first be accessed if available.

Medicaid is a Federal and state partnership in terms of funding and program design. States may design and operate their Medicaid program within Federal guidelines. With some limitations, states set their own eligibility standards, scope of program and payment for services, so there are in fact 50 different Medicaid programs, some relatively limited, and others more flexible. Medicaid includes a range of mandatory and optional services and is the largest program providing medical

health related services to America's poorest populations. Each state operates through a state Medicaid plan, approved by the Federal government.

The Federal Medicaid statute requires states to specify the amount, duration, and scope of each service they provide, which must be sufficient to reasonably achieve its purposes. States may not place limits on services or arbitrarily deny or reduce coverage of required services solely because of diagnosis, type of illness, or condition. Generally, a state plan must be in effect throughout an entire state (i.e. amount, duration, and scope of coverage must be the same statewide). There are certain exceptions to these rules. Two major ones: (a) states operating home and community based services (HCBS) waivers need not offer all services covered under the waiver to all beneficiaries in the state; and (b) targeted case management services offered as an optional benefit under the state plan are not subject to the state wideness rule. Examples of state plan Medicaid services include; home health, durable medical equipment, hospital stays, pharmacy, dental, vision, audiology and hospice.

The local SRS office, Economic Employment Support Specialist, determines Medicaid eligibility in the state of Kansas. There is an SRS office in every county in the state. All Medicaid waiver consumers must be determined Medicaid eligible before services may begin. The Federal government sets financial eligibility rules and options. The state has some flexibility in the interpretation of these rules.

Dental Services under Kansas Medicaid
Adult dental services covers limited prior authorized dental procedures associated with medically necessary extractions. For Medicaid consumers under the age of 21 routine dental services like cleaning, fluoride treatments, x-rays, sealants, fillings and extractions are covered. Some services need prior authorization thought the state fiscal agent.

Vision Services under Kansas Medicaid
For adults, eye exams are covered once every 4 years with 2 exams per month for medical conditions. Replacement of eyeglasses is covered once every 4 years. Contact lenses require prior authorization. For children, eye exams and glasses are covered as needed. Contact lenses require prior authorization.

Hospice Services
Hospice care provides an integrated program of appropriate hospital and home care for the terminally ill consumer. It is a physician directed, nurse coordinated, interdisciplinary team approach to consumer care which is available 24 hours per day, seven days a week. A hospice provides personal and supportive medical care for terminally ill individuals and supportive care to their families. Emphasis is on home care with inpatient beds serving as backup for the home care program.

Hospice services are available to Medicaid consumers who:
- Have been certified terminally ill by the medical director of the hospice or the physician member of the hospice interdisciplinary team; AND
- Have been certified terminally ill by the consumers's attending physician.

- Have filed an election statement with a hospice which meets Medicare conditions of participation for hospices.

Services that the Hospice provides include: routine home care, continuous home care, inpatient respite care, non-residential-respite, general inpatient hospital care and room and board for nursing facility.

Consumers of hospice services are eligible to receive services through the Home and Community Based Services program, as long as th HCBS services do not duplicate services being rendered by the hospice provider.

Home Health Services
Home Health Services through the Medicaid state plan include skilled nursing care; home health aide care with some medical supplies; and therapies. When ordered by a medical provider, therapies such as physical, occupational, and speech, must be rehabilitative and restorative. There is a six-month limitation on therapies. These services are available to all Medicaid consumers when shown to be medically necessary and ordered by a physician. Federal regulations allow states to establish reasonable standards for determining the extent of such coverage based on such criteria as medical necessity or utilization control.

Consumers who are receiving services through an HCBS waiver may access home health services as listed above. Home health aide services require prior authorization through the Medicaid fiscal agent due to the fact that these services many times may be provided through the a waiver in a more cost effective manner. Skilled nursing services also require prior authorization. Skilled nursing services include but are not limited to; IV therapy, injections, and blood draws. Medication administration for waiver consumers will be questioned by the prior authorization unit. The reason for this is that in many situations there is another person available that is able to administer the medication safely and in a more cost effective manner. If there is a question regarding the coverage of home health services for waiver consumers, please contact the prior authorization unit at the Medicaid fiscal agent.

HCBS 101:
The Foundation of Title XIX Home and Community Based Service Waivers

Purpose
The Centers for Medicare and Medicaid Services (CMS) gives States the opportunity to develop programs and services for special needs populations that meet their preferences in service delivery and are cost-effective alternatives to institutional care arrangements funded under Title XIX (Medicaid). States, through an application process within the Single State Medicaid Agency, SRS, contract with CMS for authority to operate HCBS programs by waiving certain Title XIX requirements as noted below. HCBS programs improve the quality of life for special needs populations while avoiding more expensive means of health care that increase costs for States.

Authority
Title XIX is a part of the federal Social Security Act that provides funding of health care services for certain groups of eligible individuals. Each State develops and submits a State Plan to CMS, which lists all of the health care services the State, intends to provide. Examples are pharmacy, physician, and hospital services. Title XIX State Plan services receive an approximate 60% match rate from CMS. State General Funds (SGF) pay the remaining 40% share of the total cost. Title XIX eligible groups include individuals who meet the financial and program requirements for Temporary Assistance to Families (TAF), Foster Care (FC) Children, Social Security for Aged, Blind and Disabled, and Supplemental Security Income (SSI). All of these eligibility groups are eligible to receive any of the Title XIX State Plan services when determined medically necessary.

Section 1915 of the Social Security Act allows CMS to waive three sections of Title XIX law in order to allow States to provide HCBS programs. Sections waived include: state wideness; eligible population; and standards of eligibility. By waiving these sections, States can choose to cover non-traditional or expanded health care services to limited populations, in limited areas or use special eligibility rules. It is the State's decision to identify some services, like case management and attendant care to be either State Plan or waiver services. The decision is usually dependent upon the population to be served and financing methodologies available. Consumers eligible for HCBS programs are Title XIX eligible and therefore receive both HCBS and State Plan services.

Responsibility for administration of the HCBS programs is within SRS as the Single State Medicaid Agency. However, the day-to-day management of the HCBS program for the frail elderly was transferred to Kansas Department on Aging in July of 1997.

Approval
States wanting to operate HCBS programs must submit a separate application for each desired HCBS program to the Secretary of Health and Human Services (HHS) on a standardized form developed by CMS. While each application is drafted to define the unique services to meet the needs of a specific population certain assurances are consistent across all HCBS waiver applications. These common elements are: a.) safeguards to protect the health and welfare of consumers; b.) means of evaluation or assessment of an individual's need for institutional services; c.) assure consumers are informed of a choice between institutional and HCBS; d.) must cost no more on average per capita to provide services than average per capita institutional care; and e.) report service and cost information to CMS annually. It takes approximately six to nine months to develop a successful waiver application and CMS requires at least three months for review and approval.

Special Populations
CMS does not specifically define special populations but allows States latitude in identifying groups of individuals with similar health care needs. Kansas has developed six HCBS programs to meet specific needs of the following special populations: 1.) frail elderly over age 65; 2.)adults and children with developmental disabilities; 3.) children who are severely emotionally disturbed; 4.) children who require technology in order to sustain life; 5.) individuals over age 16 but not over age 55 who are traumatically brain injured; and 6.) individuals over age 16 but under age 65 who are physically disabled.

Institutional Comparison Model
Once a special population has been identified to have similar needs, the State must be able to demonstrate a Title XIX reimbursed institutional model from which cost-effectiveness can be determined. For the six special populations noted above, Kansas uses the following institutional models respectively 1.) nursing facilities (NFs); 2.) intermediate care facilities for mentally retarded (ICF/MRs); 3.) State Hospitals for mentally ill children; 4.) acute care hospitals; 5.) head injury rehabilitation facilities; and 6.) NF's.
The institutional comparison model is not only used to determine cost-effectiveness but is also the basis for many HCBS rules and regulations. CMS will not allow States to develop policies or procedures for HCBS programs that would not be allowed in the institutional model. An example includes the prohibition on allowing family to financially supplement additional like services which mirror needed services that are listed on the HCBS plan of care. While families cannot financially supplement HCBS care plans, families are encouraged, when appropriate, to remain a part of the informal support system – providing unpaid/natural support for the person or financial assistance for matters not covered with HCBS care plans. Families who remain actively involved in providing care tend to help ensure quality services and cost-efficiency in HCBS.

Access and Eligibility
As a part of the HCBS waiver application process, States must define how access and the two-fold eligibility process for the program will be determined. Kansas has chosen to use private agencies, generally not-for-profit organizations, for access and functional eligibility while SRS area/local offices determine financial eligibility. The access agencies are typically those organizations with interest in service delivery and advocacy to a particular special population. The special populations noted above use the following agencies as access points respectively: 1.) Area Agencies on Aging (AAAs); 2.) Community Developmental Disability Organizations (CDDOs); 3.) Community Mental Health Centers (CMHCs); 4.) Registered Nurses in private case management agencies like KIDS SCREEN; 5.) Private case management agencies with special focus on head injury rehabilitation and Centers for Independent Living (CILs) and 6.) CILs and licensed Home Health Agencies (HHAs).

The access agencies not only provide information about the HCBS program but also provide case management functions. As a part of case management activity, private agency staff perform one component of the eligibility process. Assessment of the individuals health care status and functional abilities to determine if the person would be eligible to receive services in an institutional setting for which Title XIX would reimburse. This is referred to establishing the level of care criteria. Assessment instruments used in this process vary between HCBS programs in order to adequately determine the needs of the special population. The assessment process can take anywhere from 2 hours to two months to complete depending on the individual situation.

Plan of Care
Another integral function of case management staff is the development of the individual plan of care. The HCBS waiver requires that each individual receiving HCBS services have a plan of care that identifies at a minimum a.) the medical and other services (regardless of funding source) to be furnished; b.) their frequency (scope and duration); and c.) the type of provider who will furnish each. Care plans are a negotiated document between the consumer, if desired, his/her representative and the case manager. Copies of the care plan are shared with potential service providers to ensure

the selected provider can deliver the needed services. Qualifications for providers is defined in the HCBS waiver application. Providers have the option of refusing a service referral if they cannot meet the need.

Case Managers are encouraged to write care plans to anticipate all of the individual's needs and maximize utilization of informal support systems. By doing so, CMS is assured that adequate services have been authorized to meet the consumer's health and welfare needs in the most difficult time periods and in emergency situations while ensuring cost-efficiency as well.

Service Definitions and Reimbursement
CMS allows, even encourages, States to be creative in development of HCBS service definitions and reimbursement methodologies. Each program creates unique services to meet the needs of the intended special population. Some services, like Attendant Care, are similar in definition across all HCBS programs. However, qualifications of providers, limitations on scope and benefits, and reimbursement varies between the programs to again meet the specific needs of individuals within a special population. Some HCBS definitions in Kansas HCBS programs are very prescriptive in nature while others allow broad flexibility.

Like Title XIX State Plan services, all HCBS claims must be paid through a certified Medicaid Management Information System (MMIS). In Kansas, SRS contracts with Blue Cross/Blue Shield (BCBS) of Kansas to perform this fiscal responsibility.

Consumer Directed Attendant Care
K.S.A. 65-6201 requires that consumers age 18 yrs of age and older be allowed to self-direct attendant care services funded under the HCBS waivers. Consumers who choose this service delivery option are responsible for recruiting, training, and managing their attendants. Attendant care can be supervision or physical assistance with any Activities of Daily Living (ADL's) and Instrumental Activities of Daily Living (IADL's). Some tasks, termed Health Maintenance Activities, do require delegation from a nurse or physician.

Additional requirements for self-directed care can be spelled out in regulatory standards and affiliate agreements. A large percentage of HCBS consumers in Kansas choose to self-direct their attendants.

CMS strictly prohibits parents of minor children and spouses from receiving Title XIX reimbursement for HCBS. Other family members can be paid as attendants under HCBS programs. Caregivers selected by consumers to provide attendant care services must enroll through a "payroll agency" in order to receive Title XIX reimbursement. These agencies receive the reimbursement for attendant care from Title XIX through the MMIS and retain a certain amount for administrative overhead then pay the attendant. The payroll agencies are responsible for ensuring the appropriate federal and state withholdings are completed. Administrative costs vary between agencies but generally most payroll agencies offer benefit packages to attendants such as health insurance, retirement or childcare. Some use the administrative funds to assist in system advocacy at the community level.

Cost-Effectiveness
CMS requires that the State Medicaid agency to demonstrate on an annual basis that HCBS costs no more than what would have been expended in absence of the waiver. CMS does not look at cost-effectiveness on an individual basis, but rather in the aggregate. This allows States the option to grant exceptions to the "cost cap". All HCBS programs have established a figure which reflects the average cost of institutional care on an individual basis. This is a management tool that helps ensure the program remains cost-effective. When a consumer's needs are so great that the cost of their care in the community exceeds the cost of their care in the institutional setting, the State can consider granting an exception to the cost cap.

Quality Assurance
The waiver application requires the State to evaluate the effectiveness of its HCBS programs to ensure that the services provided meet the needs of the consumer; that the consumer's basic health and safety are protected; and that consumers who receive these services meet the level of care criteria of the institutional care model. Each of the HCBS programs in Kansas use different means of evaluation. Some use State agency staff to monitor quality and level of care while others use external quality review organizations like Kansas Foundation for Medical Care. The States proposals for quality assurance monitoring become a part of the approved waiver application with CMS. In all HCBS programs, case management is the front-line of quality assurance and is a critical component to overall quality assurance processes.

Amendments
HCBS waivers can be amended to meet the changing needs of a special population or to strengthen and ensure cost-effectiveness. Again, CMS requires at least three months to review and approve the changes. All amendments to the HCBS waiver applications must be submitted to CMS by the Single State Medicaid Agency, SRS. The CMS approved waiver application is the basis for State agencies to develop regulations, policies and procedures.

Plans of Care – MRDD Waiver Ground Rules
The plan of care is the fundamental tool by which Kansas will ensure the health and welfare of the individuals served under the waiver. The plan of care will contain, at a minimum, the type of services to be furnished, the amount, the frequency and duration of each service, and the type of provider to furnish each service.

For the MR/DD waiver the HCBS MR/DD Plan of care (MR-2) should be completed and in each consumers files. The form is part of the federally approved waiver and must be completed and signed by the consumer or their guardian.

When this is completed this information should be entered into the electronic plan of care system also know as the Prior Authorization System. The intent of the electronic plan of care system is for prior authorization and claims payment. This plan should identify and specify all services needed, including waiver services, other paid services (including Medicaid state plan services), and informal supports. These plans are electronically submitted to SRS Central office for approval (with hard copy submission for special funding plans). Please refer to the Prior Authorization Manual for this process.

In December, 1997 a policy was developed that electronic plans of care would not be approved if they were over 45 days old. The prior authorization system was developed to approve plans **prior to services beginning.** This policy remains in effect. SRS Central office will not authorize any changes in the prior authorization system older than 45 days. This 45 days is allowed in order to respond to emergencies. Therefore it is vital that when entering a plan of care into the electronic system that **ALL** information is correct, this includes provider numbers and start and stop dates.

Electronic plans of care that have had no changes made to them in the month will regenerate automatically in the system monthly, through the annual cycle. Each person's Plan of Care must be updated and resubmitted at least annually.

Basics of Waiver Programs

HCBS/MRDD Waiver

Eligibility Requirements
- 5 years of age or older
- Eligible for Medicaid
- Meeting the definition of mental retardation or developmental disability.
- Eligible for ICF/MR level of care.

Institutional Equivalent: Intermediate Care Facility for Persons with Mental Retardation

Point of Entry: Community Developmental Disability Organization

Financial Eligibility:
- Only the individual's personal income and resources are considered.
- For individuals under age 18 parents' income and resources are not counted.
- Income over $696 per month must be contributed towards the cost of care.

Services Available:
Residential Services are provided in the individual's residential setting (outside the individual's family home) providing assistance, acquisition, retention and/or improvement in skills related to activities of daily living, such as, personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting.

Day Services usually, but not necessarily, take place during "normal working hours". Day services are regularly occurring activities that provide a sense of participation, accomplishment, personal reward, personal contribution, or remuneration and thereby serve as vehicles to maintain or increase adaptive capabilities, independence or integration and participation in the community.

Medical Alert Rental provides support to a recipient who has a medical need that could become critical at any time.

Wellness Monitoring is a process whereby a registered nurse evaluates the level of wellness of a recipient to determine if the recipient is properly using medical health services as recommended by a physician and if the health of the recipient is sufficient to maintain him in his place of residence without more frequent skilled nursing intervention.

Family/Individual Supports are available to individuals who live in the family home. This service provides necessary support for individuals to meet their daily living needs and/or to insure continuation of stay in family homes. This service provides for paid staff to perform in-home assistance any hour of the night or day, in the absence or presence of non-paid care givers as determined to meet the individual's needs.

Wheelchair Modifications are modifications necessary for promoting the health, well-being and independence of the recipient.

Van Lifts are vehicle modifications consisting solely of van lifts (may include other structural changes to accommodate the lift installation), are provided for safe transfer and transportation to enhance community integration.

Supportive Home Care is available to waiver recipients who live in the birth or adoptive family home. This service provides necessary assistance for eligible persons in order to meet their daily living situation needs. A description of expectations for supportive home care workers must be maintained and available for review.

Respite Care is temporary care provided to recipients designed to provide relief for the recipient's family member who serves as primary care (unpaid) giver.

Night Support is overnight assistance to recipients in their home in case of emergencies or to assist with repositioning. A night support attendant is readily to call a doctor, hospital, or provide other assistance if an emergency occurs. The attendant must be immediately available, but can sleep when not needed. The attendant does not perform any other personal care, training, or homemaker tasks.

Communication Devices are devices, which assist in making a consumer as independent as possible in the community by allowing the consumer to communicate as clearly as possible their specific wants/desires and needs.

Home Modifications are those services which assess the need for, arrange for, and provide modifications or improvements to a recipient's living quarters to permit an individual to remain with his natural, adoptive or foster family or in an inclusive setting and ensure safety, security and accessibility.

HCBS/HI Waiver

Eligibility Requirements

- Age 16 - 55
- Have traumatic non-degenerative brain injury resulting in residual deficits and disabilities
- Eligible for in-patient care in a Head Injury Rehabilitation Hospital

Institutional Equivalent: Head Injury Rehabilitation Facility

Point of Entry: Centers for Independent Living or Home Health Agencies

Financial Eligibility:
- Only the individual's personal income and resources are considered.
- For individuals under age 18 parents' income and resources are not counted.
- Income over $696 per month must be contributed towards the cost of care.

Services Available

Personal Services means one or more persons assisting another person with a disability with tasks, which the disabled individual would typically do for himself/herself in the absence of a disability.

Assistive Services are those services, which meet an individual's assessed need by modifying or improving an individual's home and through provision of adaptive or medical equipment. Cost effectiveness should be considered along with other factors, including quality of life, and level of independence when including Assistive Services in a Plan of Care.

Transitional Living Skills primary purpose is to provide community-based services for individuals who have sustained a head injury who would otherwise require institutionalization in a head injury facility. The services are designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive, and behavioral functions within the context of the person, family and the community.

Rehabilitation Services are designed to improve the skills and adjustment of the head-injured person, integrating prevocational, educational, and independent living goals, in other to return, or maintain him/her to his/her most optimum level of functioning and least restrictive level of care.

HCBS/PD Waiver

Eligibility Requirements

- Individuals age 16 – 64 [Note: People turning age 65 on 7/1/02 or after may remain on the HCBS/PD waiver if they so choose as long as they continue to be eligible]

- Determined disabled by Social Security Administration
- Needing assistance to perform normal rhythm of the day
- Meeting Medicaid nursing facility threshold

Institutional Equivalent: Nursing Facility

Point of Entry: Centers for Independent Living or Designated Home Health Agencies

Financial Eligibility:
- Only the individual's personal income and resources are considered.
- For individuals under age 18 parents' income and resources are not counted.
- Income over $696 per month must be contributed towards the cost of care.

Services Available

Personal Services means one or more persons assisting another person with a disability with tasks, which the disabled individual would typically do for himself or herself in the absence of a disability.

Assistive Services are those services, which meet an individual assessed need by modifying or improving an individual's home and through provision of adaptive equipment.

Independent Living Counseling services include serving as point of access for Medicaid services, assessment of the consumer's service need, development of plan of care, ensuring the plans of care are cost effective and meet the consumer's basic health and safety needs, ensuring full and unbiased access to a variety of services and advocacy.

HCBS/FE Waiver

Eligibility Requirements
- Individuals age 65 and over
- Needing assistance with activities of daily living
- Meet Medicaid nursing facility threshold

Institutional Equivalent: Nursing Facility

Point of Entry: Area Agencies on Aging

Financial Eligibility:

- Only the individual's personal income and resources are considered.
- Income over $696 per month must be contributed towards the cost of care.

Services Available:
Adult Day Care is designed to maintain optimal physical and social functioning for consumers.

Sleep Cycle Support provides non-nursing physical assistance and/or supervision during the consumer's normal sleeping hours in the consumer's place of residence, excluding nursing facilities.

Emergency Response systems provide 24 hour a day on-call support to the consumer having a medical or emergency that could become critical at anytime.

Health Care Attendant provides physical assistance with activities of daily living and instrumental activities of daily living for individuals who are unable to perform one or more activities independently.

Wellness Monitoring provides health status monitoring through nursing assessment. This service reduces the need for routine physician/health professional visits and care in more costly settings.

Respite Care provides temporary relief for primary caregivers of consumers. This service may be provided for varied periods of time in a location agreed to by the consumer, caregiver, and case manager.

HCBS/SED Waiver

Eligibility Requirements
- A youth must be between 4 and 22 years old, although an exception may be requested for a child younger than 4.
- An Axis 1 diagnosis must be present
- All youth on the waiver must be identified as SED
- A youth must be determined as likely to need a state hospital level of care in the absence of waiver services.
- All youth on the waiver must meet minimum scores on the Child Behavior Checklist (CBCL) and Child and Adolescent Functional Assessment Scale (CAFAS).

Institutional Equivalent: State Mental Health Hospital

Point of Entry: Community Mental Health Center

Financial Eligibility:
- Only the individual's personal income and resources are considered.
- For individuals under age 18 parents' income and resources are not counted.
- Income over $696 per month must be contributed towards the cost of care.

Services Available:

Independent Living/Skill Building Services are designed to assist children and adolescents in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings.

Parent Support and Training benefits Medicaid-eligible children through activities in his/her home and community. Includes coaching and assisting the family with increasing their knowledge and awareness of their child's needs, the process of interpreting choice offered by service providers, explanation and interpretations of policies and procedures and regulations that impact the child living in the community.

Respite Care provides short term and temporary direct care and supervision for youth. The primary purpose is to relieve families/caretakers of a child with severe emotional disturbance. The service is designed to help meet needs of primary caretakers as well as children.

Wraparound Facilitation/Community Support involves the assessment of the child's and family's caretaker's strengths and needs for community relationships and involvement and determine overall need of the level of community-based waiver and non-waiver services. Produces an individualized community-based plan to access and be part of informal community resources and develop relationships to help the child succeed in the community.

HCBS/TA Waiver

Eligibility Requirements
- Children under the age of 18
- Dependent on mechanical ventilators
- Need intravenous administration of nutritional substances or drugs
- Need substantial ongoing care in a hospital setting
- Not otherwise eligible for Medicaid

Institutional Equivalent: Acute Care Hospital

Point of Entry: Private Agencies

Financial Eligibility:
- For individuals under age 18 parents' income and resources are not counted.
- Income over $696 per month must be contributed towards the cost of care.

Services Available
Respite Care is temporary care provided to recipients designed to provide relief for the recipient's family member who serves as primary care (unpaid) giver.

Medical Equipment and Supplies that are not covered by Medicaid.

Case Management

General Information
- If a person is eligible to receive MRDD waiver services, he should be served with that waiver (even if also eligible for PD waiver services).
- If a person has both MRDD waiver service needs and mental health service needs, the MRDD service system is expected to take the lead in service development and access, including access to effective mental health services.

Non-Waiver Services

Community and Family Services and Supports
These are services and supports funded by State General Funds allocated to each CDDO for Family Support, Family Subsidy and Adult Day and Adult Residential Services. These funds are utilized based upon individual need. These services can supplement other non waiver services the person may be receiving, such as Infant/Toddler services. Each person who receives state general fund services must have a Person Centered Support Plan in place. The only exception to the Person Centered Support Plan requirements is for those receiving direct financial support alone.

Persons currently receiving services from one CDDO or CSP may move to another CDDO or CSP. All funds with the exception of state aid and CDDO administration funding must be portable. Funds must be portable except when a person no longer needs services or voluntarily withdraws from services with no immediate foreseeable need for services.

Food Assistance Program

The Food assistance program (also knows as the food stamp program) provides benefits to eligible persons to buy food, even vegetable plants and seeds, from a local grocery store. The cost is electronically subtracted from the person's Vision card account. The Vision card looks and acts like a debit card.

Basic Eligibility Requirements:
- Persons age 60 and older and persons with disabilities are eligible for this program
- Persons with disabiities include those receiving Supplemental Security Income, Social Security disability payments, certain Veterans disability payments, disability retirement benefits for a permanent disability, and railroad retirement disability. Persons who work, but have a low income, as well as those who do not work are eligible.
- The person and anyone who lives in the person's household and eats with the person are eligible. Household members do not have to be related to be considered part of the household. This would include unrelated individuals who live in a group home.
- All the household members must be United States citizens or meet other non-citizen qualifications.

The amount of assistance received is based on the household's size and amount of income after deductions. Deductions include monthly expenses such as rent, gas, electric, and phone charges.

The person can have up to $3,000 in resources if one person in the household is age 60 or older or has a disability. Resources include cash, checking, and savings accounts. Certain resources like a home and car are not counted.

Receiving food assistance will not reduce the amount of other payments received such as Social Security or Supplemental Security Income. There are no time limits on receiving food assistance as long as the person meets the requirements.

Applying for food assistance is easy. An application can be picked up at the local SRS office, or one can be mailed to the person. Return the completed application to SRS and the person will be notified of an interview date. The person does not have to come to the SRS office for the interview. People with disabilities who have difficulty getting around can ask the food stamp office to arrange a home visit or telephone interview. People with disabilities may also name an authorized representative, who can complete the food stamp application process for them or can assist or accompany them.

The person will need to provide SRS with proof of identification and assets as part of the application process. Once a person is determined eligible, SRS notifies the person and informs them of the amount of food assistance they will receive. The person will need to obtain their initial Vision card at the local SRS office and then on a monthly basis, SRS will add funds to their Vision card account. The Vision card is presented to the store clerk when purchasing food and the amount of the purchase is electronically deducted from their account balance.

Emergency Food Assistance Program (TEFAP)
The Emergency Food Assistance Program (TEFAP) provides United States Department of Agriculture (USDA) food to low income households. This food provides help in improving the diet and is free of charge for qualifying households. Food is shipped four or five times a year to local nonprofit organizations and food banks, who are responsible for notifying the public of the time and place of distribution. Information regarding the location of participating organizations and distribution dates can be obtained from local helping agencies or SRS offices.

Basic Eligibility Requirements:
• Resident of Kansas
• A declaration of eligibility must be signed prior to receiving USDA commodities at a participating organization
• Provide income and household size information
• Verification of income and household size, if requested, must be provided
• Resident must apply in the county of residence, or where established by a distribution area plan
• Additional requirements may be added by local distributing organizations

In some cases, a representative of the person can pick up the commodities and the person does not have to be present. Contact the participating organization prior to the distribution time to find out the specific procedures to follow since each organization may have different practices.

Medicare

Medicare is a federal health insurance program for people 65 or older and people with certain disabilities. It is administered by CMS Department of the U.S. Department of Health and Human Services (HHS). Social Security offices take applications for Medicare and provide general information about the program.

There are two parts to Medicare:
- **Part A or Hospital Insurance** - This helps pay for: Care in hospitals as an inpatient, critical access hospitals, some skilled nursing facilities, hospice care, and some home health care. Part A is paid for by a portion of the Social Security tax of people still working.

- **Part B or Medical Insurance** - This helps pay for: Doctors' services, outpatient services, hospital care, supplies that are medically necessary and some other medical services that Part A does not cover, such as the services of physical and occupational therapists, and some home health care. There is a monthly premium for Medicare Part B coverage and the premiums may change yearly. Once a person is eligible for Medicare Part A, they automatically become eligible for Medicare Part B. The monthly premium for Part B is usually taken out of the person's monthly Social Security or Railroad Retirement checks. If the person doesn't get any of these payments, Medicare sends a bill for the Part B premium every three months.

Medicare Premium Program
Persons who are eligible for Medicare Part A coverage and whose income does not exceed 100% of the federal poverty level (eligible for QMB) or falls between 100% and 175% of the federal poverty level (eligible for LMB) can qualify for the Medicare premium program.

The person must be a resident of Kansas and either a U.S. citizen or a qualifying alien. The person must also provide or apply for a Social Security number and cooperate with the agency in providing all information necessary to determine eligibility.

Generally, all resources owned by the individual except the home and one automobile must be counted. This includes checking accounts, savings accounts, other real estate, trust funds, etc.

The earned and unearned income of the person and any appropriate family members must be counted. This includes wages, unemployment benefits, and Social Security and VA benefits. Certain income is exempt by federal statute and regulation such as some educational grants and SSI benefits. Unearned income is generally counted in full. Certain deductions are applied to earned income.

The Qualified Medicare Beneficiary Program (QMB) will pay for the individual's Medicare premiums, deductibles and co-payments, if their resources are under the limits and if their income is under 100% of the federal poverty level.

The Low Income Medicare Beneficiary Program (LMB) will pay for all or a portion of an individuals Medicare premiums if their resources are under the limits and their income is between 100% and 175% of the federal poverty level.

Kansas Rehabilitation Services (KRS)

Vocational Rehabilitation (VR) services are designed to help people with disabilities become gainfully employed and self-reliant. The program emphasizes individualized community-based services, integration, and consumer choice. Services may include vocational assessment; counseling and guidance; physical and mental restoration; training; rehabilitation technology; job placement, supported employment, and transition planning services for students with severe disabilities.

Eligibility criteria for VR services are defined by the Federal Rehabilitation Act. To receive services, an individual must: have a physical or mental impairment that results in a substantial impediment to employment; be able to benefit, in terms of an employment outcome, from VR services; and require VR services to prepare for, secure, retain or regain employment. Priority is given to those with the most severe disability when there are insufficient resources available to serve all eligible applicants. Payment for most services is based upon the individual's financial need.

During the past three years (1999 on), Rehabilitation Services has changed the way vocational assessment and supported education services are provided. Instead of being offered primarily at centralized facilities, these services are now available in a greater number of community settings. More than 50 percent of the Rehabilitation Services budget through private providers. Services offered through these public-private partnerships include supported employment, transitional employment, job placement, employment preparation, and support.

For assistance or more information regarding vocational rehabilitation services, contact the Client Assistance Program. CAP provides ombudsman services to VR and independent living applicants and consumers. Contact can also be made through the local SRS office, Division of Vocational Rehabilitation.

Assistive Technology for Kansans

The Assistive Technology for Kansans (ATK) Project helps persons with disabilities find ways to live and work as independently as possible through the use of assistive devices and services. The primary mission of the project is to engage in activities that are designed to result in laws, regulations, policies, practices, or organizational structures that promote consumer-responsive programs that increase access to assistive technology devices and services. The Project is guided by an Executive Advisory Board made up of individuals with disabilities, family members, and representatives from state agencies.

The Project has the following components:

- **Interagency Equipment Loan System**
  OCCK, Inc., operates the Equipment Loan System. Through the statewide loan system, individuals with disabilities have the opportunity to try devices before purchasing them and to borrow equipment during emergencies or while completing funding arrangements to purchase equipment.

- **Funding and Policy Analysis Division**

The Kansas Association of Centers for Independent Living (KACIL) develops, implements, and monitors state, regional, and local laws, regulations, policies, and practices, to improve access to assistive technology devices and assistive technology services.

- **Annual Statewide Conference**
  The Capper Foundation coordinates an annual statewide conference each fall to showcase assistive technology in Kansas. A large vendor hall, hands-on assistive technology lab and in-depth pre-conference workshops are also a part of this annual event.

- **Legal Services**
  Kansas Advocacy and Protective Services (KAPS) has the legal contract with the Project to provide legal services which result in addressing systems change issues within the state. This contract focuses on timely access to and funding for assistive technology for Kansans with disabilities.

- **Regional Assistive Technology Access Sites**
  Five Regional Assistive Technology Access Sites were established to provide information regarding assistive technology to their region. The Access Sites work to coordinate assistive technology resources and respond to specific consumer needs. The Access Sites are linked with the Interagency Equipment Loan System and provide training and technical assistance to consumers and agencies in their regions. Individuals with disabilities and agency or organization representatives direct the activities of the Access Sites. To contact the Access Site in your region, call 1-800-KAN DO IT (1-800-526-3648)--Kansas Only.

- **Project Management**
  The statewide Project is coordinated through the University Affiliated Program at Parsons. Project staff provide training, technical assistance, Project management and evaluation services, and Access Site equipment.

Kansas Telecommunications Access Program

The Telecommunications Access Program (TAP) of Kansas will provide vouchers for specialized telecommunications equipment for people with certified disabilities who need assistance in utilizing the telephone.

Eligibility Requirements:
- An applicant must be a Kansas resident.
- An applicant must have telephone service in home.
- An applicant must have a certified disability that requires specialized equipment to effectively use the telephone.
- An applicant's annual adjusted gross income does not exceed $55,000 per household ($3,000 may be added to the $55,000 income threshold for each dependent claimed for income tax purposes).

To apply for a TAP voucher, send a completed application to the address on the application. If the application is approved, a voucher will be issued to the applicant in an amount equal to the market price of the equipment requested. If the applicant is also approved for a signaling device, two vouchers will be issued. The voucher(s) will be mailed to the applicant along with a list of approved vendors. The voucher recipient is responsible for purchasing or ordering their equipment. Our-of-state vendors may be used if they have been approved by TAP.

Contact information:
Kansas Telecommunications Access Program
700 SW Jackson, Suite 704
Topeka, KS 66603-3758
785-234-0200 – Voice
785-234-0207 – TTY
785-234-2304 – Fax
E-mail: tap@kstelecom.com

Low Income Energy Assistance Program

The Low Income Energy Assistance Program (LIEAP) is an annual program that is designed to help a household with its heating costs. The program is operational each year between mid-January and the end of March. Applications can be filed at any SRS office. A special application form must be filed. Applications are available at any SRS office, at heating utility companies, through the Department of Aging and other various helping and service agencies.

Eligibility for LIEAP is based on several factors:
• The household must be responsible for a heating cost, either through direct billing to an adult household member or through the landlord, or have heating included in the rent.
• Income for the three months prior to the month of application must be considered (gross, i.e. before taxes and deductions) and must be less than 130% of the poverty level
• The household must prove that it has made energy payments in at least 2 of the last three months.
• If eligible, a one-time payment is made. The amount of the payment will vary from case to case, and is based on household income, size, type of home/apartment, type of furnace and type of heating fuel.

This payment comes in the form of a two-party check made payable to the head of household and the utility company. For Kansas Gas Service customers, payment is made directly to KGS. If the household has separate heating and cooling bills, payments may be split between the two utilities.

Social Security Benefits
There are five major categories of benefits paid for through Social Security taxes: retirement, disability, family benefits, survivors and Medicare. Supplemental Security Benefits are not financed by Social Security taxes, however they are a part of the Social Security system. Of

these five categories disability benefits and Medicare would be of the most interest to the persons served.

Disability benefits are payable at any age to people who have enough Social Security credits and who have a severe physical or mental impairment that is expected to prevent them from doing "substantial" work for a year or more or who have a condition that is expected to result in death. The disability program includes incentives to smooth the transition back into the workforce, including continuation of benefits and health care coverage while a person attempts to work.

Supplemental Security Income (SSI)
The federal government makes payments to people who have a low income and few assets. To get SSI, the person must be 65 or older or be disabled. Children as well as adults qualify for SSI disability payments. As its name implies, Supplemental Security Income "supplements" the person's income up to various levels - depending on where the person lives. The federal government pays a basic rate and some states add money to that amount. Generally, people who get SSI also qualify for Medicaid, food assistance programs and other assistance.

To apply for SSI, the person must go to the local Social Security Administration (SSA) office. She or he will need to bring all the applicable documents from the following list:
• Social Security card
• Birth Certificate
• Information about his disability (i.e. medical or psychological reports)
• Earned income records (i.e. paycheck stubs, tax returns)
• Unearned income reports (i.e. child support, alimony, or interest records)
• Real estate records
• Auto registration
• Information about liquid assets (i.e. checking and savings account statements for four
  months, bonds, stock certificates, and life insurance policies)

Eligibility for SSI is determined by Disability Determination and Referral Services (DDRS) from Topeka, KS, however applications must be made at the local SSA office. Kansans who receive SSI are also eligible for Medicaid

Social Security Disability Insurance (SSDI)
People with long-term or indefinite disabling conditions severe enough to prevent them from working, and who have worked in the past and contributed to Social Security, are eligible for SSDI. Adult children with disabilities who are "dependents of retired or deceased workers" are also eligible for Social Security benefits "if the dependent's disability began prior to age 18."

The application process for SSDI is similar to that for SSI, including the documentation needed. The amount of SSDI paid monthly will depend upon the amount the worker contributed to Social Security.

Kansans who receive SSDI may or may not be eligible for Medicaid, depending on the size of their monthly benefit and other resources and income.

Housing Assistance Programs
The Housing Development Division of the Kansas Department of Commerce and Housing and the U.S. Department of Housing and Urban Development provide housing assistance for people in the State of Kansas. In some cases, the Kansas Department of Commerce and Housing provides the oversight for Department of HUD funds awarded in this State.

The goals of both the State and Federal Housing Departments are similar and they utilize a variety of strategies and approaches to create housing opportunities for the residents of Kansas. The most common strategies are increasing homeownership opportunities, promoting energy efficiency improvements for owner-occupied and rental housing, and providing affordable housing through rent assistance to low-income families.

- **Home Ownership**
  As the cost of rent increases, many of the people receiving services are wanting to purchase their own homes. Most banks and lending institutions have loan programs to help fund the home purchase. The Rural Development offices located throughout the State offer another option for funding home purchases. Their staff are very knowledgeable and have a variety of programs such as First Time Home Buyer Program, Interest Deferred Loans and many others that are actually superior to the traditional loans. In some cases, funding is provided for the down payment and the person makes the monthly mortgage payments.

- **Section 8 Rental Vouchers and Certificates**
  HUD provides Section 8 rental vouchers and certificates administered by Public Housing Authorities (PHAs) that have approved plans. The voucher and certificate program increases affordable housing choices for very low-income households by allowing families to choose privately owned rental housing. The PHA generally pays the landlord the difference between 30 percent of household income and the PHA-determined payment standard - about 80 to 100 percent of the fair market rent (FMR). The rent must be reasonable. The household may choose a unit with a higher rent than the FMR and pay the landlord the difference or choose a lower cost unit and keep the difference.

  The administering PHA inspects the housing units to make sure they comply with HUD quality standards. The PHA issues a voucher to an income-qualified household, which then finds a unit to rent. If the unit meets the Section 8 quality standards, the PHA then pays the landlord the HUD portion and the tenant is responsible for the remainder of the rent. The rent must be reasonable compared with similar unassisted units.

  A system of "portability" allows families to use the assistance outside the boundaries of the PHA that originally admits a family. HUD pays the administering agency an administration fee to cover costs of running the program, including accepting and reviewing applications, recertifying participants, and inspecting the rental units for quality.

  Applications must be completed through the local Public Housing Authority.

- **Kansas Accessibility Modification Program**

  The Kansas Accessibility Modification Program (KAMP) is administered by the Kansas Department of Housing and Commerce. It is a pilot program designed for two basic purposes: 1) to provide accessibility modifications to residences allowing individuals to better fulfill their abilities to use their homes, and 2) to gather information for future planning about the need in our state for such modifications.

  If a person owns their home, they can qualify for up to $4,500 in modifications and if the person rents, they may be eligible for up to $2,000. The person needs to submit a completed application, income verification (such as a copy of their income tax return or a signed statement from the employer or Social Security), two bids, and landlord approval if the person is renting.

  There are several locations throughout Kansas that process the applications for KAMP funds. To receive an application call 1-800-KAN-DO-IT and ask for the Assistive Technology department.

- **Weatherization Assistance Program**
  The State of Kansas and the Federal Government fund Weatherization Assistance Programs. The goals for both programs are to provide housing improvements that increase energy efficiency in income-eligible, single- or multi-family dwellings, including manufactured homes. Contact the local SRS office for an application.

  Eligibility income guidelines for the Kansas Weatherization Program differ from LIEAP and are 150% of the federal poverty level or 60% of the state median income, whichever is greater. Households are automatically eligible if one person is receiving Temporary Assistance to Families (TAF) or Supplemental Security Income (SSI). There is no resource test. The elderly, people with disabilities, or those with at least one child in the home are identified as a special population, which deems them a priority when a waiting list for services develops. Emergency situations also receive priority (e.g., furnace tests positive for carbon monoxide).

  Weatherization services and materials may include: weatherization needs assessments; caulking; insulation; storm windows; modifications, repairs, or replacements of heating or cooling system. Contact the local SRS office for an application.

Taxing Rebates/Refunds:
State of Kansas - Homestead/Food Sales Tax and Federal IRS Deductions

- **Homestead Tax Credit**
  The State of Kansas offers a property tax rebate of up to $600.00 for homeowners and renters. To qualify, the claimant must be a Kansas resident whose household income was less than $25,000 (2001), and who is over 55 years old, or is blind or has disabilities, or has a dependent child under 18 who lived with them all year. "Household income" is generally the total of all taxable and nontaxable income received by all household members.

This rebate is claimed on Kansas Form K-40H, "Kansas Homestead Refund Claim." This form and booklet of instructions are available from the Taxpayer Assistance Center, driver's license stations, the county clerk's office and other places of convenience throughout the state, or by calling voice mail forms request line (785) 296-4937.

- **Food Sales Tax Refund**
  Form K-40 is not only a Kansas Income Tax return, but also the claim form for the Food Sales Tax Refund. This program offers a refund of the sales tax paid on food. To qualify, you must be 55 years of age or older, or be blind or have disabilities, or have a dependent child under 18 who lived with you all year whom you claim as a personal exemption. You must also be a Kansas resident whose Kansas qualifying income is $25,000 (2001) or less. The refund is claimed on Form K-40. The Food Sales Tax refund will either increase the amount of your Income Tax refund or decrease the amount you owe.

- **Federal IRS Deductions**
  The Federal IRS offers tax breaks to people with disabilities as they are filing their taxes. Medical expenses related to the person's disability are deductible as well as special items and equipment, which are necessary for the care of the individual. Supplemental Security Income (SSI) payments are not taxable and these payments should not be included in the person's income. For more information on Credits for the Elderly or the Disabled, see IRS Publication 524.

CDDO/CSP-Based Special Needs Funds

Many CDDOs and CSPs have restricted funds set aside for special needs of persons with disabilities. Each CDDO and CSP will have their own policies on how to access the funds as well as what the funds can be used for. Some CDDOs and CSPs may grant the money and others may loan the money with a required pay back plan. The most common items the restricted funds are used for are: security deposits on rent and utilities, start up costs for initial apartment setting or group home setting, dental expenses, uncovered medical expenses, and assistive technology.

The CDDOs and CSPs attempt to find other funding for the requests prior to using their restricted funds. They may work with local civic organizations, religious organizations, ARCs, Goodwill, State Agencies and foundations to fund the request. Many communities have Salvation Army, Food Pantries, or Assistance Centers available to help provide food and clothing to people in need.

Advocating for Benefits

The case manager should assist the person and advocate for access to any of these programs for which the person is eligible. If the person is denied any benefits to which he may be entitled, the case manager should assist him in appealing.

Spenddown/HCBS Patient Obligation

Background

Under Medicaid rules, States are mandated to provide medical assistance for persons that are eligible for either AFDC or SSI cash benefits. In addition, there are also mandates for coverage of children and pregnant women under poverty level guidelines as well as other groups such as children in foster care and adoption support. These groups are referred to as the "categorically needy."

States also have the option to cover persons who would be eligible for one of the programs listed above except for income. This group is referred to as the "medically needy." Kansas has historically operated a medically needy program and coverage is currently provided to children up to age 18, pregnant women, and the elderly and disabled. Coverage can also be provided to caretaker relatives of dependent children such as parents, grandparents, aunts and uncles but Kansas eliminated this coverage in September 1991. The medically needy concept allows for persons with income in excess of the categorically needy standards to "spenddown" that excess through application of medical expenses and thereby qualify for medical assistance.

Spenddown Process
The spenddown provisions are contained in the federal regulations. Those provisions require that a State establish income standards against which the individual's or family's countable income is compared. If the income is at or below the standard, the person is eligible. If the income exceeds the standard, the amount of that excess is the person's spenddown. In essence, it is similar to an insurance deductible in that the person is required to meet the amount of the "deductible" (spenddown) before coverage is provided. The spenddown is met through application of medical expenses.

The process works like this. As an example, an applicant is determined to have $350 in monthly countable income (after allowable deductions). The monthly income standard for one individual is $300. In this instance, the spenddown would be $50. The applicant would then be required to incur $50 in medical expenses before becoming eligible. The expenses do not have to be paid to be allowed against spenddown, only incurred. Once the spenddown is met, the Medicaid program would pick up the remainder of the person's expenses but would not pay for the $50 in expenses used to meet spenddown. If, in this example, the individual has incurred medical expenses of $150, he or she would be obligated for $50 of that amount and Medicaid would pick up the remaining $100.

Medical expenses which can be used to meet a spenddown include any medically necessary service prescribed by a medical practitioner including inpatient and outpatient care, prescription costs, office visits, medical equipment, Targeted Case Management bills, etc. The expenses do not have to be covered under the State's Medicaid program so costs such as eye and dental exams which are generally not covered in Kansas for adults would be allowable. In addition, the cost of any medical insurance the person has is also applicable to spenddown. However, any medical costs which are picked up by a third party insurer cannot be counted against the spenddown. Only those expenses for which the individual is obligated to pay on his or her own can be used. Expenses used can be either ones incurred during the budget period described below or past expenses, which the person still owes.

States have the option of using a budget period to determine a spenddown of from one to six months. Kansas uses a six-month period for persons in independent living arrangements. Thus, in the above example, six months of income ($350 x 6 = $2100) in comparison to a six month income standard ($300 x 6 = $1800) would result in a spenddown of $300 ($2100 - $1800 = $300). Once this spenddown is met, the person is eligible for coverage on all other expenses incurred during the 6-month period. A new spenddown is then calculated for the next 6-month period and so on.

HCBS Patient Obligation Process
For those persons who receive Home and Community Based Services Waiver (HCBS) as the funding for their services and where their monthly income exceeds a protected income level, their spenddown is called a patient obligation. The HCBS patient obligation is the monthly amount of their obligation toward medical services that must be paid in order to retain the Medicaid card. The patient obligation is calculated by SRS, in some cases, on a monthly basis and others on an annual basis with annual redetermination. The person's monthly patient obligation can either be met by reimbursing the HCBS provider for the monthly amount or by submitting eligible due and owing medical expenses to SRS for reduction on a future months patient obligation. Paying the monthly patient obligation ensures the person receiving services will retain the Medicaid card. SRS Economic Assistance Specialists calculate the monthly patient obligation based on the person's monthly earned and unearned income less the protected income limit. The difference becomes the monthly patient obligation and is payable to the service provider. The service provider deducts the amount of the monthly patient obligation from their HCBS Medicaid service billings.

It is the responsibility of the person receiving services to pay any medical bills that were used to meet or decrease the monthly patient obligation. They should not be submitted to Medicaid. It is also the responsibility of the person to pay the monthly patient obligation in a timely manner to the service organization. Failure to make timely payments could result in loss of their Medicaid card, which may mean the person, would have to pay privately for their services, medical bills, prescription bills, etc.

Least Restrictive Environment

The concept of supporting persons with disabilities in the least restrictive environment involves choice and integration into the community. Choice is the expression of preference, or active selection among two or more alternatives, based on prior experience, current needs, and future goals. Supporting persons with developmental disabilities in the least restrictive environment is creating services, responsive to the person's needs, in various environments, that provide choice and integration.

Serving people in the least restrictive environment includes prevention of unwanted/unnecessary intensive medical services, admission to a state DD hospital, admission to an ICF/MR, admission to a mental health hospital, and/or admission to nursing home. Case managers for people with developmental disabilities need to be involved in planning and monitoring of services to help ensure

community based services, coupled with available natural supports/generic services, are consistently accessed to meet well-identified needs for the person's success. If access to ICF/MR or state DD hospital services are being contemplated, the case manager should work with the CDDO, who must facilitate any application for those services, and should keep the Quality Enhancement Coordinator informed of the situation.

Serving persons in the least restrictive environment includes creatively preventing the need to access and addressing supports when a person transitions from a medical hospital, state DD hospital, an ICF/MR, a mental health hospital and/or a nursing home. Options that may be available are:

- Temporarily increasing paid or natural supports.
- Accessing a temporary respite site or other change in environment.
- Enacting a person centered emergency plan, with resources established, specific to the situation and the person's needs.
- Accessing assistive technology.

Natural Supports

The concept of assisting persons with disabilities to locate and maintain natural supports has been growing and developing over the past ten years throughout the nation. Thankfully, individuals with disabilities are no longer shunned by our society and are active members of our shared communities. They are at the grocery stores, in churches, at the library, employed in the community and present on the sidewalks and streets of Kansas. Years ago, these same individuals would have been behind the walls of nursing homes, in hospital beds, or in other institutions --- seemingly forgotten. As a case manager, an important part of your job is to assist persons in obtaining natural supports responsive to the person's choices and needs which will provide them with the greatest level of integration and inclusion into the communities in which they live.

Natural Supports are defined as the supports that are provided by non-paid friends, relatives, neighbors, co-workers and others in the community. Everyone has some natural supports in their lives and a good service provider will assist a person to expand their network so he is not dependent on just a couple of family members or paid support staff. Natural supports are needed to help stretch the limited resources available for paid supports, and also to enhance the quality of lives for people who need assistance in daily life.

Integration into the community is the use of the same community resources by persons with developmental disabilities as those being used by persons without disabilities such as: stores, post offices, historical societies, recreation facilities, medical facilities, restaurants, etc. Integration means that individuals with disabilities have regular community interaction and participate in the same activities as persons without disabilities. They also live in homes which are in proximity to community resources.

Inclusion is the right of all persons, with or without disabilities, to experience love and friendship, to experience continuity in their lives, especially in relation to the people who are important to them, and to be respected and treated with dignity. Many times people with disabilities feel isolated, especially when the only people they interact with are paid staff. Think of it -- how would you feel

if every one of the people you considered your friends were paid to be with you. After a period of time, you might wonder if they were your true friend or if they were friends because they were being paid. It has been shown that people who have natural supports have higher self-esteem.

Identification of natural supports is an integral part of every individual's person centered support plan (PCSP). The current natural supports should be identified and documented in the PCSP and the person and their support network should think "outside the box" – creatively and expansively – to develop alternative natural supports to replace paid supports whenever possible. New natural supports should be identified to help meet the person's choices and needs. When identifying a person's natural supports, avoid the pitfall of using the same natural support excessively -- that person will begin to feel taken advantage of. When natural supports are accessed successfully, interdependent relationships naturally form and true friendships emerge.

Generic Services

Generic community services refer to services available to all individuals in the community, such as: physicians, dentists, other medical professionals, pharmacies, senior centers, community centers, stores, transportation services, churches, criminal justice victim assistance, support groups, restaurants, etc. These generic community services are listed in your area phone book or other local reference materials. In order to offer or assist the individual in gaining needed services or supports the case manager utilizes this vast network of resources to connect the individual to the appropriate resources. The person centered support plan is the tool used to identify needs and determine available resources to ensure services are being provided. Ongoing revisions and regular reviews reflect changes to respond to individual needs.

Some information that may be helpful in thinking about generic resources follows. However, each case manager should become informed about what local resources are available in their communities:

Mental Health and Substance Abuse Prevention Treatment and Recovery (MHSAPTR): The goal of MHSAPTR is to provide support to individuals and families who experience mental illness and/or substance abuse problems.

Mental Health Services: over the past two decades the state has steadily moved mental health service from a primarily institutional based system, to a system that seeks to provide services through community settings. This effort has resulted in increased funding for the development of community-based programs and services, as well as increased coordination, collaboration, and integration between the community mental health centers (CMHCs) and state hospitals.

The primary local coordinating agency for community-based mental health services is the licensed CMHC. There are 27 CMHC's in Kansas and two licensed affiliates. The licensed affiliates specialize in services to children and their families. There is a greater emphasis on the delivery of services to persons with the most serious illnesses-the target populations. In Kansas, the target populations are adults with severe and persistent mental illness and children with severe emotional disturbance.

Contact your local CMHC for further information. Licensed comprehensive CMHC's offer the following required basic services: Outpatient Clinical Services: 24-hour emergency services; Consultation and Education; Screenings, Aftercare; Case Management; Medication management.

Community Support Services (CSS) is the program within CMHC's that offer specialized services to adults with severe and persistent mental illness. Case management is the core service of CSS. Contact your local CSS for further information. Besides case management, other in-home and community-bsed services available through CSS include: Medication management; Attendant care and individual community support; Psychosocial and educational activities; Supported employment and vocational programs; Housing and residential programs; Respite/Crises stabilization services; Connections to consumer run organizations and consumer-focused activities.

Services for children in the targeted population are generally organized at the local level by the Community Based Services Programs of the CMHCs for children/adolescents with SED. In addition to providing the above-required services, all CMHC's offer an array of community based mental services to children and adolescents with SED. Case management is the core service of a community based treatment approach. Other services may include but are not limited to: Home-based Family Therapy; Partial hospitalization; Attendant care; Respite care; wraparound services; Psycho-social rehabilitation programs; Parent support and education services.

All licensed CMHCs statewide also provide at least one specialized mental health service for children and adolescents.

MHSAPTR also oversees the operation of three State Mental Health Hospitals (SMHH). Theses are Larned State Hospital, Osawatomie State Hospital, and Rainbow Mental Health Facility. The primary goal of SMHH placement is the stabilization of consumers who are experiencing acute symptoms in a safe and therapeutic environment.

Case managers supporting people with developmental disabilities should keep these points in mind when the people you support also have mental health service needs: First, there are substantive differences between the supports you provide and those provided by people who perform case management in the mental health system. If needed and eligible to receive such services, it is feasible that someone you support with case management may also benefit from case management services in the mental health system. Second, if someone you support has both developmental disabilities and mental health diagnoses, the general rule is that the developmental disabilities service system should take the lead in supporting the person – but access mental health services as needed and available. It may be important for you to advocate for the person you support in accessing appropriate mental health services.

Substance Abuse Treatment and Recovery (SAPTR): administers state and federal funds, assures quality of care standards, promotes effective public policy, and develops and evaluates programmatic and human resources to reduce tobacco, alcohol and other drug use in Kansas.

For additional information regarding services provided by SRS/Health Care Policy or their contracting partners, please visit the web site at www.srskansas.org.

Services for Children with Special Health Care Needs (CSHCN): promotes the functional skills of young persons in Kansas who have or are at risk for a disability or chronic disease by providing or supporting a system of specialty health care. CSHCN provides diagnostic, treatment, outreach, and special services to youth under the age of 21 who live in Kansas, have a medical condition covered by the program, and meet the financial guidelines. Contact one of the CSHCN offices listed or any local public health department or major hospital social service department for information, assistance, or application forms. Referral may be initiated by any concerned person.

> Services for Children with Special Health Care Needs
> 1000 SW Jackson, Suite 220
> Topeka, KS 66612-1274
> (785) 296-1313
>
> Field Offices
> CSHCN
> Kansas Department of Health and Environment
> Suite 202, 3243 E. Murdock
> Wichita, KS 67208
> (316) 688-2021
>
> Special Health Services, KUMC
> CDU, Room 1005
> 3901 Rainbow Blvd.
> Kansas City, KS 66160-7340
> (913) 588-6343
>
> Make A Difference Information Network
> (800) 332-6262

Kansas Association of Centers for Independent Living: the governing body of all Independent Living Centers that have a primary mission of advocating for the independent living needs of Kansans with disabilities. Independent Living Centers strive to develop new resources and to identify and provide access to existing resources that provide for personal independence and community choices. The following services, or referral for services, may be available in your area; Information and referral, Skills training, Peer support, Advocacy and outreach, Assistive devices/equipment, Personal assistant services, and Volunteer providers.

Kansas Legal Services (KLS): a statewide non-profit organization, is dedicated to helping low income Kansans meet their basic needs through the provision of essential legal, mediation and employment training services. KLS provides: access to justice program; alternative dispute resolution services; children's legal services; employment training programs; public benefits and

disability law. They operate twelve legal services, two mediation and seven employment training offices. For client intake, first contact 1-800-723-6953.

Kansas Legal Services
712 L. Kansas Ave., Suite 200
Topeka, KS 66603
(785) 233-2068

Rights and Responsibilities

As a case manager you are the primary advocate for the individual's rights and services. You are not the guardian's advocate nor the service provider's or the CDDO's advocate. Your primary responsibility is to the person served.

Documentation: Developmental Disabilities Reform Act
                      Kansas Lifestyle Outcomes - Second Edition (KLO 2nd)
                      The U.S. Constitution

Resources: Kansas Advocacy and Protective Services, Inc.
                      Jim Germer, Executive Director
                      3745 S.W. Wanamaker Road
                      Topeka, KS 66610
                      1-800-432-8276

                      Kansas Council on Developmental Disabilities
                      Jane Rhys, Executive Director
                      915 S.W. Harrison, Room 141
                      Topeka, KS 66612-1570
                      1-877-431-4604

                      Self-Advocate Coalition of Kansas
                      Jeanne Abraham-Lunz, Advocacy Coordinator
                      2518 Ridge Court, Room 236
                      Lawrence, KS 66046
                      1-888-354-7225

What follows does not intend to be an exhaustive list of individual rights and responsibilities for persons with developmental disabilities but may be helpful starting point. Please refer to the documents and resources listed above for more information.

Individual Rights and Responsibilities Supported
The person, his/her guardian and support network have ongoing, individually appropriate opportunities to learn about his/her individual rights and responsibilities, including at least quarterly training.

- The person actively participates in matters impacting his/her life, including decision-making, all aspects of support planning and implementation, activities of self care (such as shopping, meal planning and preparation), home/property care (such as housekeeping, selection and purchase of personal property, and choosing his/her daily routine and daily activities.

- The person has time, space and opportunities for privacy, including closed doors, no one entering personal space without seeking permission, private telephone, visiting and grooming/dressing space, private mail.

- The person is supported in exploring, accessing and exercising his/her religion.

- The person is supported in exploring, accessing and exercising his/her right to vote.

- The person is not being required to work without compensation (except in upkeep of the person's own living space and of common areas of shared home), including assisting with the care and support of other people receiving services.

- The person has control over his/her financial resources; or, if any support is needed to assist the person in managing financial resources, safeguards are in place to ensure appropriate use of the funds, access to funds and information by the person or his/her representative, and accountability for all funds. Even if a guardianship/conservatorship is in place in the person's live, he/she should have access to information about his/her finances if desired.

- The person and guardian have been provided individually appropriate information regarding his/her rights to confidentiality, to access records, and to decide with whom to share information.

- The person and guardian have been provided individually-appropriate information regarding how to access dispute resolution processes if disputes arise concerning his/her services, including such processes both for his/her services provider and for the CDDO region and beyond to Fair Hearing.

- Both the person and the guardian are assisted in resolving any conflict that arises between them, and are supported in understanding their respective rights, roles and responsibilities, as well as the person's preferences in regard to the conflict. Again, remember here the case manager needs to advocate for the person s/he supports and not necessarily the guardian.

- The person is treated with dignity, respect and fairness; is listened to, responded to, and treated as an adult.

- The person reports feeling safe and secure in all of his/her environments; or if not, proactive measures are in place to effectively detect and address the cause(s).

- Restrictive practices are not utilized without safeguards, including informed consent, insuring that it is the least restrictive practice, the presence of related positive supports, and review/approval by a behavior management committee.

Self-Determination
Self-Determination is a service style that supports people to have greater control and flexibility over the delivery of services. The core principles of self-determination are freedom, support, authority and responsibility. The Self-Determination funding option establishes mechanisms by which people have direct control and responsibility for the dollars spent to provide services. People control these dollars and use them to buy services directly or to build their own unique service systems.

The purpose of this section is to provide some very general information about:
- The history of Self-Determination in Kansas
- National trends in Self-Determination
- The structure of the Kansas Self-Determination program
- The future of Self-Determination programs in Kansas

History
The Kansas Self-Determination program began in 1997 with a grant from the Robert Wood Johnson foundation. This grant provided Kansas with a staff person and start-up money for two sites, TARC in Topeka and COMCARE in Wichita, to begin to develop the infrastructure to deliver the Self-Determination funding option to individuals. The Kansas Council on Developmental Disabilities also provided funding for sites at OCCK (Salina area) and CLASS, Ltd. (SE Kansas). People have also accessed self-determination through Cottonwood, Inc. (Lawrence). These sites have been working to develop the infrastructure for the utilization of self-determination. Eventually, the goal is to support the structure of self-determination as an option for people statewide.

National Trends
Nationally, the Self-determination Funding Model is being implemented with great success. The self-determination movement has provided an avenue for people to exercise their right to make decisions about their own lifestyles. They are deciding where they live, who they live with, and what type of a community they want to live and work in. Individuals who are utilizing the self-determination model are using their existing network of friends and circle of supportive others to broaden their experiences and contribute to their communities in valuable and meaningful ways. The idea of individuals with developmental disabilities assuming greater responsibilities for their actions and decisions, becoming self-advocates, communicating their dreams, and finding creative ways to make their dreams work is spreading nationally. Many are beginning to take advantage of this unique approach to developing their own ideal lifestyle.

Currently, there are approximately 31 states who are moving their service delivery toward self-determination for persons with developmental disabilities. A great deal has been going on retraining and restructuring traditional case management, and educating people, family members, and other support people, about the principles of self-determination and the unique opportunities available. Kansas has moved way ahead of many states in exploring and utilizing self-determination, as the idea of "self-direction" and person centered support planning has long been an approach to individual lifestyles for individuals with developmental disabilities. Kansas was implementing many of the self-determination values way before self-determination became an available funding model.

Kansas Structure

In Kansas, some sites have a Self-Determination Coordinator, usually someone who works for the CDDO. A person who chooses Self-Determination will begin by working with their Circle of Support (similar to the team that meets to discuss the Person-Centered Plan). This team includes family, friends, community members and support professionals. The purpose of this team is to provide ongoing support to ensure the success of the person. In this way, this team differs from the Person-Centered Planning team, in that they will meet frequently to help the person address various community needs. The case manager plays a major role in coordination of the Circle and in the success of the Circle.

The Circle of Support helps develop an individual budget for a person. This budget takes into account all dollars the person has access to: income from a job, social security and money from Medicaid waiver services. With this budget, the person then purchases appropriate services or uses the budget to build their lifestyle. Some people who need very specialized services have used the pooled dollars to pay a professional support staff a salary and benefits. Others have used the money to start their own business. Other purchases can include specialized Assistive Technology or accessibility adaptations to make a home more livable. The budget allows people who would like some different support options the ability to develop those free from some of the restrictions traditional services provide.

After the budget is developed, a fiscal intermediary is established to receive the dollars and distribute them to the various paid supports. For a nominal fee, some accountants will keep track of the person's budget, write checks to support staff or for other support needs and keep track of employment taxes and other important items.

The Future of Self-Determination

Self-Determination is currently only a service style utilized in the Comcare, TARC, OCCK, Cottonwood and Class, Ltd. service areas. The model, however is being developed so that it can be a service option statewide. It also only available for people on the MR/DD Waiver. The goal is that self determination service style will be developed as an option for all people with disabilities by July 1, 2003.

For more information on Self-Determination in Kansas, contact Greg Wintle at: wgw@srskansas.org

Module 5: Monitoring And Follow Up

Implementing the Person Centered Support Plan

The person-centered support plan (PCSP) is a "working" document that needs constant review and revision by the person and his/her support team.

Why is review of the plan necessary?
- to ensure services and supports agreed to in the PCSP are being provided;
- to measure progress and/or achievement of goals and objectives;
- to determine if the preferred lifestyle in the PCSP is consistent with the person's current needs and lifestyle preferences, and with what is happening in the person's life; and
- to ensure that the person's needs are being met.

How often should the plan be reviewed?
- Regulation requires that the PCSP be reviewed on a regular basis. "Regular" is based upon the current needs of the person served and should be outlined in the PCSP.
- Monthly, quarterly or every six month reviews are all standard practice.
- An unscheduled review may be prompted by significant changes in the person's life.

What should the review include?
- personal "face-to-face" contact with the person served;
- personal or verbal contact with the person's support staff and network;
- observation of services being provided in the setting where they are typically provided;
- written documentation of each of the above contacts;
- sharing/reporting information obtained during the review process to the appropriate party (i.e. Quality Assurance Committee, Behavior Management Committee, SRS, etc.)

What types of questions should be asked during the review?

Preferred lifestyle
- Is the person living in the type of setting that was described in the PCSP?
- Is the person living with whom was described in the PCSP?
- Is the person participating in the work or other valued activity as described in the PSCP?
- Is the person socializing with others as described in the PCSP?
- Is the person participating in the social, leisure, religious and other activities as described in the PCSP?
- Is the current preferred lifestyle of the person consistent with what was described in the PCSP?
- Are there any barriers preventing the person from achieving their preferred lifestyle? If so, how are they being addressed?

Goals and objectives
- What specific goals and objectives were identified in the PCSP?
- Is documented progress being made towards those goals and objectives?
- Are there any barriers to achieving any of the PCSP goals and objectives?
- Is it appropriate to continue the goals and objectives as identified in the PCSP?

Health Care Supports
- Are the health and medical needs of the person being addressed as outlined in the PCSP?
- Is the health care coordinator actively coordinating the person's health care? Do they need assistance?
- Have all medical issues been addressed in a thorough and timely manner?
- Is the person receiving all the medical attention they need on a regular basis and as needed?
- Are all preventive care and health management procedures known and followed (i.e. special diets, restricted activities)?
- Is all equipment needed for personal care or medical treatments readily accessible, in good repair, and being consistently utilized?
- Have changes in medical condition been communicated to support network to assure continuity of care?
- Is the person served refusing medical care? Is it documented? Is further review needed?
- Is wellness monitoring up to date? Are all noted concerns being addressed?
- Is the person achieving greater independence in meeting their health care needs?
- Has effectiveness of medications been documented?
- Have any side effects been noted? If so, has appropriate follow up occurred?

Behavioral support needs
- Are the behavioral support needs of the person being addressed as outlined in the PCSP?
- Is there a behavioral support plan in place? Do all persons responsible for implementation have a copy?
- Is the behavioral support plan adequate to address the needs of the person served?
- Is there documented progress towards targeted behavior(s)?
- Does the current behavior warrant a behavioral support plan?
- Is there consistent documentation of the frequency and severity of behaviors?
- Have any incident reports been filed?
- Are positive behavioral supports being consistently delivered?
- Are there any environmental factors affecting the person?
- Is informed consent present for any restrictive practice?

Additional training and supports
- Are the relationship needs of the person being addressed as outlined in the PCSP?
- Are the financial needs of the person being addressed as outlined in the PCSP?
- Are the self-advocacy needs of the person being addressed as outlined in the PCSP?
- Are the personal safety needs of the person being addressed as outlined in the PCSP?
- Are there any barriers to meeting the needs listed above?
- Are the supports and training described in the PCSP still appropriate to meet the needs of theperson served?
- Have any reports been made to Adult Protective Services? If so, has the issue been addressed and corrected? Is the person still at risk?

Decision making and choices
- How are opportunities of choice being supported? Is this consistent with the PCSP?

- Is the person communicating in their preferred mode as outlined in the PCSP?
- Are staff communicating to the person in their preferred mode of communication?
- Is the person served making decisions in accordance with their level of ability and as outlined in the PCSP?
- Are training and supports, as outlined in the PCSP, being provided to enhance the person's level of decision making?
- Are there additional supports and training necessary to increase decision making skills?
- Is the person making decisions or engaging in behavior that puts their health, safety or welfare in jeopardy?
- Is there a risk assessment in place? Is one needed?
- If there is a risk assessment, is it being followed?
- Is the person served being supported to exercise and understand their rights and responsibilities?
- Is there any practice in place that is limiting the person's access to any person, place, or thing? Are the safeguards in place to implement this practice?

Overall and In Summary
- Is the person making progress? Is the person satisfied with their progress?
- Do all persons responsible for implementation of any part of the PCSP have the tools, skills and knowledge to carry out their duties?
- Do all persons responsible for implementation of any part of the PCSP have a clear understanding of their role and responsibility?
- Is the PCSP consistent with the current needs of the person served?
- If there are barriers to implementing any of part of the PCSP, what steps are being taken to address the barriers? Can more be done to assist the person?
- If any part of the PCSP can not be implemented because of financial limitations, have those limitations been clearly identified and do they meet the requirements set forth in regulation?
- Is revision to the PCSP needed because of changes in the preferred lifestyle, barriers to achieving preferred lifestyle or delivering outlined supports, or achievement of PCSP?
- If revision is needed, the TCM should meet with the person and their support network to develop an addendum to the PCSP. (Approval by the person or person served is necessary to implement revised changes to the PCSP.)

What types of additional items should be reviewed during an on-site visit?
- Incident/accident reports
- Behavioral data
- Seizure reports
- Daily documentation of residential and day services provided
- Medication Administration Records/Medication Error Report Forms
- Storage of Medication (Is it appropriate for the person?)
- Adaptive devices (i.e. ramps, eyeglasses, shower chairs, etc)
- Current information on medications including purpose and side effects
- Emergency preparedness practices and skills
- Maintenance and cleanliness of the day and residential service settings
- Accessibility and adequate space
- Safety equipment (i.e. smoke detector, TDD, etc)

Kansas Lifestyle Outcomes (KLO) 2nd

What is it?
- The KLO 2nd is a quality assurance tool used by Social and Rehabilitation Services (SRS) for individualized and comprehensive surveys of persons receiving services.
- This tool assists in determining the level to which outcomes related to licensing standards and responsiveness to personal needs/lifestyle preferences are present in the lives of persons served.

Who is surveyed?
- The 370-person survey samples are randomly drawn twice a year from persons served reported in BASIS.
- The sample includes 5% of all persons served from every Community Developmental Disabilities Organization (CDDO) area.
- Both licensed and non-licensed (i.e. supportive home care) services are surveyed.
- Any licensed service provider that serves more than five persons must be included at least once a year in the survey.

What does the KLO 2nd measure?
- The KLO 2nd measures the presence or absence of licensing outcomes as defined in Article 63 Licensing Regulations, as well as the responsiveness of services.
- Specifically, the KLO 2nd focuses on the following areas:
  - ▸ whether an appropriate person-centered support plan is in place and being implemented;
  - ▸ whether individual rights and responsibilities are supported;
  - ▸ whether services are provided in healthy and safe environments;
  - ▸ whether medications are managed appropriately; and
  - ▸ whether necessary behavioral supports are being utilized with required safeguards.

Who does the KLO 2nd?
- The Quality Enhancement Coordinators (QEC's) complete the KLO 2nd.

What happens during the KLO 2nd?
- During the assessment process the QEC will visit all sites where services are provided to the individuals who were selected for the sample, review pertinent records, and interview the person served, their guardian, and their support network as necessary.
- Individuals served and their families should be made aware by their service provider that their name has been drawn for the survey and should have a basic understanding of the process.

What happens after the KLO 2nd is completed?
- When the survey is completed, the QEC will review the results with all involved providers and the CDDO.

- If outcome measures do not meet standards, the providers and CDDO will need to correct those items.
- The specifics of the corrective action plan will be negotiated between the providers and the CDDO and the QEC.
- If systemic deficiencies are noted, the license status of the provider may be affected.
- Survey results are published and distributed statewide.
- Results are reported by CDDO or provider only, and individual information is kept confidential.

Abuse, Neglect and Exploitation

Note: The purpose of this module is to provide some basic overview information about key substantive issues involving abuse, neglect and exploitation, as well as some core regulatory and service provider standards. This module is not designed to make you, as the case manager, fully informed about all abuse, neglect and exploitation issues, which are many and sometimes complex. You should obtain additional related training about these subjects and be familiar with the related policies and practices of agencies providing services to people you support.

The State of Kansas has enacted laws to protect children and vulnerable adults from abuse, neglect and exploitation (ANE). Social and Rehabilitation Services (SRS) is responsible to investigate reports and has two separate divisions - Child Protective Services (CPS) and Adult Protective Services (APS).

Child Abuse
Kansas Child Abuse law recognizes physical injury, physical neglect, emotional injury, sexual exploitation and sexual abuse.

Definitions
- Physical abuse constitutes any physical injury of a child by non-accidental means.
- Sexual abuse is any sexual act, such as indecent exposure, improper touching to penetration that is carried out with a child
- Sexual abuse may be committed by a person under the age of 18, when that person is either older than the victim or when the abuser is in a position of power or control over another child
- Sexual Exploitation is the employing, using, persuading, inducing, enticing or coercing a child under the age of 16 years to engage in sexually explicit conduct for the purpose of prompting any performance.
- Emotional Abuse is the consistent, chronic behavior by a parent or caregiver that has a harmful effect on the child. It involves a pattern of attitudes or acts that are detrimental to the child's development and impairs the child's social, emotional or intellectual functioning.
- Physical Neglect is the failure or inattention on the part of the caregiver or parent, to provide for the child's basic needs such as food, clothing, shelter, medical care and supervision.

Adult Abuse
A vulnerable adult is defined as any individual 18 years or older alleged to be unable to protect their own interest and who is harmed or threatened with harm through action or inaction by either another individual or through their own action or inaction when (1) such person is residing in such person's

own home, the home of a family member or home of a friend, (2) such person resides in an adult family home as defined in K.S.A. 39-1501 and amendments thereto, or (3) such person is receiving services through a provider of community services and affiliates thereof operated and funded by SRS or the Department on Aging or a residential facility licensed pursuant to K.S.A. 75-3307b and amendments thereto.

Abuse Definitions

Abuse means any act or failure to act performed intentionally or recklessly that causes or is likely to cause harm to an adult, including:
▸ infliction of physical or mental injury;
▸ any sexual act with an adult when the adult does not consent or when the other person knows or should know that the adult is incapable of resisting or declining consent to the sexual act due to mental deficiency or disease or due to fear of retribution or hardship;
▸ unreasonable use of a physical restraint, isolation or medication that harms or is likely to harm the adult;
▸ unreasonable use of a physical or chemical restraint, medication or isolation as punishment, for convenience, in conflict with a physician's
▸ orders or as a substitute for treatment, except where such conduct or
▸ physical restraint is in furtherance of the health and safety of the adult;
▸ a threat or menacing conduct directed toward an adult that results or
▸ might be reasonably be expected to result in fear or emotional or mental distress to an adult;
▸ fiduciary abuse; or
▸ omission or deprivation by a caretaker or another person of goods or services which are necessary to avoid physical or mental harm or illness.

Physical Abuse
● infliction of physical or mental injury
● unresonable use of restraint, isolation or medication
● use of restraint, isolation, or medication as punishment, convenience, in conflict with physician's orders, or as a substitute for treatment
● conduct listed above may be acceptable when the person's health and safety is in jeopardy (i.e. physically restraining a person who is engaging in self-injurious behavior).

Examples of physical abuse (actions of the offender)
▸ Slapping, Spanking, Beating, Hitting, Striking, Pushing, Throwing or Shaking
▸ Intentionally withholding food, medications, supports and equipment
▸ Forcing a person to eat obnoxious, unclean or harmful substances
▸ Unnecessary restraining
▸ Abandonment
▸ Hiding a walker, dentures, glasses, etc.
▸ Refusal to allow travel, visits by friends, attendance at church or forcing church attendance
▸ Interference with decision-making activities beyond what is necessary
▸ Ignoring symptoms of depression or mental distress

Actions of the offender are not limited solely to this list. Additionally, there are many physical and behavioral indicators of abuse, and displaying one or more of them may not always be a sign of abuse.

Sexual Abuse
- Is any sexual act with an adult when the adult does not consent or when the other person knows or should know that the adult is incapable of resisting or declining consent to the sexual act due to mental deficiency or disease or due to fear of retribution of hardship.
- In human service agencies, sexual interaction between employees and individuals receiving services is strictly prohibited.

Examples of Sexual Abuse (actions of the offender)
- Sexual relations not including actual penetration
- Sodomy
- Fondling
- Viewing the genitals
- Engaging in pornography
- Unnecessary nudity
- Stimulating the person
- Masturbating in front of the person
- Exposing oneself
- Soliciting, coercing or manipulating the individual into prostitution

Actions of the offender are not limited solely to this list. Additionally, there are many physical and behavioral indicators of sexual abuse, and displaying one or more of them may not always be a sign of sexual abuse.

Verbal / Emotional Abuse
- Any threat or menacing conduct that results or may reasonably be expected to result in fear or emotional or mental distress to an adult.
- Verbal Abuse refers to any degrading, dehumanizing, menacing, or threatening communication used against a person. Verbal abuse refers to oral, written, gestured or technologically-produced communication within the person's hearing or viewing distance regardless of the person's age or ability to comprehend.

Examples of Verbal or Emotional Abuse (Actions of the offender)
- Screaming, shouting
- Cursing, humiliation
- Name calling
- Belittling, using demeaning labels
- Intimidation
- Disrespectful attitude, Sarcasm
- Yelling, cruel teasing
- Threatening Violence
- Discriminatory Remarks

- ► Ridiculing Condition
- ► General Harassment
- ► Mimicking, telling lies
- ► Ridiculing Heritage
- ► Sexual Harassment
- ► Threatening withdrawal of food, shelter, care, clothes, possessions or necessary equipment
- ► Verbal abuse could include staff to staff conversation that is disrespectful toward the person receiving services.

Actions of the offender are not limited solely to this list. Additionally, there are many physical and behavioral indicators of verbal or emotional abuse, and displaying one or more of them may not always be a sign of abuse.

Neglect
- Failure or omission by one's self, caretaker or another person to provide goods or services which are reasonably necessary to ensure safety and well-being and to avoid physical or mental harm or illness.
- If person served is harmed by another person served, or repeated incidents are causing harm to a person served, the incident(s) is considered neglect by SRS when it is reasonable to expect the incident(s) could have been avoided by the person/agency responsible for providing care, services, or supervision.
- Neglect includes failure to:
  - ► Act as a responsible caregiver
  - ► Provide proper nutrition, shelter, clothing, education, stimulation and/or medical care
  - ► Protect a person from social and physical danger
  - ► Provide the services and supports needed to maintain minimum health and safety requirements
  - ► Provide adequate oversight of medications and restrictive interventions
  - ► Coordinate medical services

Actions of the offender are not limited solely to this list. Additionally, there are many physical and behavioral indicators of neglect, and displaying one or more of them may not always be a sign of neglect.

Exploitation
- Misappropriation of an adult's property or intentionally taking unfair advantage of an adult's physical or financial resources for another individual's personal or financial advantage by the use of undue influence, coercion, harassment, duress, deception, false representation or false pretense by a caretaker or another person.
- The misuse of property or taking unfair advantage of a person's money or physical resources and using them for your own gain.
- Fiduciary abuse is when a person who is in a position of trust takes, secretes or appropriates money or property for use not in the due and lawful execution of such person's trust.

Examples of Exploitiation (Actions of the offender)

- ‣ Mismanagement of funds, taking cash, stealing
- ‣ Charging personal expenses to the credit card of another
- ‣ Spending the person's money
- ‣ Coercing a person to pay for one's own expenses
- ‣ Coercing a person to give away property or possessions
- ‣ Coercing a person to sign papers regarding financial assets
- ‣ Withholding another person's funds
- ‣ Coercing a person to name a specific beneficiary
- ‣ Forging the signature of the person
- ‣ Not allowing an individual to discuss financial or legal matters with others
- ‣ Unexplained long distance phone calls
- ‣ Evidence of telephone or mail order scams

Actions of the offender are not limited solely to this list. Additionally, there are many physical and behavioral indicators of exploitation, and displaying one or more of them may not always be a sign of exploitation.

Reporting
- It is not the responsibility of the TCM to diagnose or confirm suspected abuse, neglect or exploitation.
- It is not the responsibility of the TCM to determine guilt or innocence.
- It is the TCM's responsibility to protect individuals from further harm, by coordinating and assisting in access to needed supports and services.
- It is the TCM's responsibility to report suspected abuse, neglect and exploitation of both children and adults to SRS immediately.
- The TCM is required to cooperate with any SRS investigation.
- The TCM is a mandatory reporter and as such cannot be held criminally or civilly liable for any involvement with reports made in good faith.
- Agencies cannot hinder or prohibit reports to SRS. Additionally, agencies cannot take adverse action against employees who make a report in good faith.
- The penalty for failure to report suspected abuse, neglect and exploitation is a Class B misdemeanor which is punishable up to 6 months in jail and/or up to a $15,000 fine. In addition, systemic failure to immediately report could negatively impact the TCM's license to provide services.
- Failure by the TCM to report may also be reported to SRS and investigated as neglect.

How to make a report
- Follow your agency's written policy on reporting.
- Call the ANE Hotline at 1-(800) 922-5330. There is someone at this number 24 hours a day, 7 days a week.
- Monday - Friday, 8am - 5pm, you may call the Area SRS office.
- The 1-800 # and area office numbers can both be used for adult or child abuse.
- Call your local law enforcement to report emergency situations or criminal actions.
- Call the Medicaid Fraud hotline at 1-800-432-9313 to report misuse or abuse of Medicaid funds.

- Call the Social Security Administration Hotline at 1-800-368-5779 to report misuse or abuse of SS funds.
- YOU MAY REPORT ANONYMOUSLY.

Information to include in your report to SRS
Note: The following information is generally going to be helpful in this process; however DO NOT feel you must wait to get all of this information before making a report - you must report immediately. You can follow up an initial call with additional information, and can offer to do so at the time of your initial report. In addition, do not limit yourself to this list when making the report – respond to all questions asked of you during the intake process, to the best of your ability, with follow up as necessary or helpful.

- Your report should be factual and specific. Report all the facts as you know them and give as much of this factual information as you can.
- Name, address, age and date of birth of the alleged victim(s).
- Name, address, age and dates of birth of any other individuals who may be at risk in the home or area.
- Name, address, age of the alleged perpetrator(s).
- Describe the functioning status of the alleged victim(s).
- Describe the current condition of the alleged victim, physically and emotionally.
- Describe any statements by the alleged victim(s).
- Describe any behavioral signs by the alleged perpetrator or threats.
- Describe any acts of omissions that you have seen/ or any overt acts of aggression.
- Describe any environmental conditions.
- Describe the frequency and/or patterns of these indicators that may show a relationship to a possible alleged perpetrator or location.
- Describe any actions you have already taken.
- If you choose to, give your name, office address, phone number and title.
- Do not include personal opinions, value judgements, or assumptions.

Confidentiality
- All elements of the SRS investigation are confidential and will be reviewed only in an official investigative capacity.
- Details of the investigation should not be shared with anyone who is not an integral part of the person's support network.
- The victim or their guardian, the perpetrator, and the executive director of the service provider organization are notified of the outcome of the investigation.

After the call is made to SRS
- The report is reviewed by SRS staff who either screen the report in and refer to a licensed social worker for investigation or screen the report out (which may be referred to the SRS Quality Enhancement Coordinator for follow up.)
- Reasons the report may be screened out include: the person(s) or the incident don't fit the description in the law, no credible reason for suspecting ANE, SRS does not have statutory

authority to investigate, malicious or spite report, or incident was previously investigated by SRS.
- SRS does not automatically investigate every death as potential ANE; if there is any reasonable suspicion that ANE may be involved in the death event or circumstances surrounding the death, it should be reported similar to any other suspected ANE.
- As a reporter, you will not be notified of the technical results of the investigation and findings from the report. However, you should monitor to assure that the substantive issue creating the report has been addressed.

After the call is screened in for investigation
- Contact is made with the victim within 24 hours for eminent danger; 3 days if the report involves neglect or less than imminent danger; 5 days if the report involves exploitation.
- The SRS social worker will interview the alleged victim(s), alleged perpetrator(s), and anyone else with information about the incident.
- The SRS social worker has 30 working days to make a determination.

Determinations or "the finding"
- Unconfirmed: A reasonable person would not believe abuse, neglect, exploitation or fiduciary abuse exists or occurred.
- Potential Risk: A reasonable person cannot conclude that evidence is sufficient to determine a confirmation but the facts and circumstances would cause a person to believe that risk of abuse, neglect, exploitation or fiduciary abuse exists.
- Confirmed: A reasonable person would conclude that more likely than not abuse, neglect,exploitation or fiduciary abuse has occurred.
- If ANE is confirmed, the perpetrator's name will be placed on the SRS
- registry after an opportunity for appeal. This registry is accessible to CDDO's and their affiliates, Mental Health facilities, Independent Living Centers, and persons who self direct their services to check abuse history of applicants for employment.
- If abuse is confirmed in an agency, the QEC will work with the agency on a corrective action plan to prevent future ANE.

If you are accused of ANE, you do have rights
- You have the right to be treated with respect and dignity
- You have the right to ask authorities to identify themselves
- You have the right to be informed of your legal rights
- You have the right to know the allegations against you
- You have the right to be informed as to the possible results that may occur from the allegations against you
- You have the right to appeal a confirmed finding
- You have the right to be informed as to the findings of the investigation

Other TCM Considerations
- You should provide education/information to people you serve and their supporters about letting you know if they have a situation involving ANE and/or if they have reported an instance of ANE.

- You should advocate for people you serve if they get reported as a perpetrator of alleged ANE. Remember that the purpose of the ANE process is to address instances in which people who have taken the responsibility for caregiving do not adequately meet and/or abuse that responsibility. For example, if you provide TCM to Bill Jones, and Bill is reported for ANE because he his punched Sam Stevens, you should advocate for Bill because the protective service process is not applicable to him. If there was a gap in services which reasonably should have been available, ANE reporting may be applicable for the service provider – but not for Bill. And, if Bill is "confirmed" as a perpetrator, you should work actively with him to understand his rights and assist him in accessing the appeal process. (If you experience this type of situation, you may contact your QE Coordinator for assistance as well.)

Module 6: Supporting Children and Families

The service philosophy of Social and Rehabilitation Services, Community Supports and Services (SRS/CSS), is that all children, ages birth to eighteen, with developmental disabilities, have every opportunity to live with their natural or adoptive families in a home environment. To that end, there are family support services, including family cash assistance, accessed through the CDDO, whose purpose is to prevent out of home placement or institutionalization. These services are based on assessed need and funded either by the Home and Community Based Waiver (HCBS) (for children five and above who are eligible), or a CDDO grant, Children and Family   Support Services, (for

children birth to 18). Children and Family Support Services help to cover the cost and/or relieve the stress of supporting a child with MR/DD. These services may assist a family with purchases of durable medical equipment and supplies, specialized formula, in–home support, respite care, direct financial support, emergency needs, specialized summer camps or any number of needs the family may have. Children and Family support services may be direct cash assistance, which is used at the family's discretion, and can be paid quarterly or monthly as per policies of the CDDO or CSP. The CDDO sets the eligibility criteria a determines the amount(s) allocated per family or child.

When children do not meet eligibility criteria for the HCBS MR/DD waiver, they may qualify for other waiver programs. These programs are as follows:

Attendant Care for Independent Living (ACIL)
>   Eligibility: Children under age 21 years and on Medicaid
>   Dependent on daily nursing care and technology to survive, but are medically stable.
>   Without assistance they would likely be institutionalized.

Home and Community Based Services – Severe Emotional Disorder (HCBS-SED)
>   Eligibility: Children under 22 years (must be receiving services before age 18 to continue through 21)
>   Diagnosed as Severely Emotionally Disturbed
>   Meets admission criteria for a State Mental Health Hospital

Home and Community Based Services – Physical Disability (HCBS-PD)
>   Eligibility: Persons age 16 to 64 years [Note: People turning age 65 on 7/1/02 or after may remain on the HCBS/PD waiver if they so choose as long as they continue to be eligible]
>   Physically disabled (not developmentally disabled or mentally ill)
>   Needs personal assistance with daily activities

Home and Community Based Services – Technology Assisted (HCBS-TA)
>   Eligibility: Children under age 18 years
>   Dependent on ventilator or intravenous method for nutrition and medication administration
>   Hospitalized or at imminent risk for hospitalization
>   Requires level of care provided by hospital

Home and Community Based Services – Head Injured (HCBS-HI)
>   Eligibility: Persons 16 to 65 years
>   Diagnosed with Traumatic Brain Injury resulting in residual deficits and disability

The role of the child's case manager, is to support and assist the family in locating services to care for their child. This involves understanding the dynamics of the family and helping them to understand what services and options are available, so their choices will be based on solid and accurate information. These services may take the form of any of the primary case management elements, including:

Assessment - such as, helping the family identify support issues, the child's needs, and resources that are available to help meet the child's needs and help the child remain successful in the home.

Support Planning - such as, facilitating the development of a person centered supporting plan, reviewing the plan with the family on a regular basis, encouraging the family to be involved with training their support workers.

Support Coordination - such as, assisting the family to find options for service providers, helping with funding/benefit applications and accessing services, encouraging the development and use of natural supports and generic community services for children and families with or without disabilities, advocacy with/for the family to secure needed benefits for their child or address/protect individual needs/rights.

Monitoring and Follow Up - such as, monitoring the implementation of and quality of services and supports, and assisting in accessing needed enhancements in services.

Transition and Portability - such as, assisting the family to make plans and arrange for services when the child moves between service providers, service settings, service types and settings (like educational, residential and/or work settings).

It is important to remember that families may be composed of primary parents (birth or adoptive), secondary parents (foster and step-parents), grandparents, siblings, and extended family members which can include relatives and close friends of the parents and child. The case manager must know who has the right to make decisions for the child. In many situations, it is appropriate to ask the family for a copy of the court order that sets forth custody arrangements. To determine who makes decisions for a child in state custody (a Child In Need of Care – CINC, police protective custody, foster care or waiting for an adoptive placement), the case manager should contact the child's SRS social worker for guidance.

Case Management services may be billed to Medicaid if the child has been determined Medicaid eligible. If the Child does not have Medicaid, case management may be paid from private funding.

If extraordinary circumstances exist that make it impossible or unsafe for the child to live in their own home, then there are some out of home residential service options available for children.

Residential services for children with developmental disabilities include foster homes and private and public institutions. If the child is in SRS custody, placement in a foster home is arranged by private contractors. The foster homes are licensed by the Kansas Department of Health and Environment. Funding for children in SRS custody who are in residential services, and/or who are being released from SRS custody as part of a permanency plan in transitioning to adult services at age 18 or thereafter, are exempt from the CDDO's fiscal year allocation as part of a contractual agreement between SRS and the CDDOs.

Some Community Services Providers, affiliates of CDDOs, have recruited and developed foster homes in their areas that serve children with developmental disabilities and are licensed by the Kansas Department of Health and Environment.

Private, non-Medicaid funded institutions such as Lakemary Center, Heartsprings and The Capper Foundation are available to children who cannot be supported in foster care. Public, Medicaid funded institutions such as the Children's Unit at the University of Kansas Medical Center and

Children's Mercy Hospital provide diagnostic/evaluation services and medication reviews for children with developmental disabilities. Parsons State Hospital (PSH) and Kansas Neurological Institute (KNI) are state mental retardation hospitals. Parsons State Hospital provides some long- and short-term inpatient, behavioral treatment for children, but no younger than age six. Inpatient services for children should be considered as a last option, and every effort should be made through proactive and consistent supports, as well as effective responses to crisis situations which arise, to help children and families succeed in their communities. PSH also provides short term, emergency respite care, on site behavioral/psychiatric consultation/evaluation, training of community staff, medical consultation and dental services. They perform outpatient evaluation/consultation for speech/hearing and OT/PT adaptive equipment. KNI provides outpatient dental services and behavioral consultation to community service providers.

The CDDOs are the gatekeepers to the State Mental Retardation Hospital. To access any of the state hospital services, referrals must be reviewed and approved by the area CDDO, and an application must be completed and submitted by the CDDO designated staff for the requested service(s). The gatekeeping process is chaired by the CDDO and ideally involves the person being referred, his guardian, support network, case manager, Quality Enhancement Coordinator for the area, and any agency or person who has knowledge of the person and his/her situation and can make a meaningful contribution. Services from the state hospital cannot be accessed without an application approved by the CDDO.

Children are placed in SRS custody by the courts for a variety of reasons: abuse and neglect are the most common.

Privatization of family preservation services, foster care and adoption services began in July of 1996. Before privatization, SRS operated the foster care system. Private contractors now operate the foster care system. SRS continues to be responsible for child protective services. The child protective services worker investigates reports of child abuse and neglect, identifies and assists the family in obtaining family services and ultimately determines if removal of the child(ren) from the home is necessary. In the case of removal, SRS petitions the court for state custody. While in foster care, the custodial agency should apply for SSI for a child who has mental retardation or developmental disabilities. Eligibility could change if parental income is considered when the child returns home. When a child leaves SRS custody, it is necessary to reapply for Medicaid.

Children's Residential Services formerly known as Supported Family Living (SFL) is a service funded through Home and Community Based Services and therefore provided to children ages 5-21 who have mental retardation or developmental disabilities. Children younger than 5 are funded solely through the Children and Family Policy division of SRS. The purpose of these services is to avoid placement in an institution or other congregate residential settings if a child is unable to remain with their natural families. This service can be utilized whether a child is in SRS custody or not. Providers are licensed child placing agencies which recruit and train caregivers. Foster homes are licensed by the Kansas Department of Health and Environment (KDH&E) and regulated jointly by SRS and KDH&E. The MR/DD case manager and the child placing agency staff monitor the services provided by the care providers as outlined in the initial agreement for each individual placed. Payment for residential services for children is based on an assigned tier level. Up to twenty percent (20%) of the HCBS/MR waiver reimbursement may be retained by the child-placing agency to defray administrative costs.

Foster homes funded by the HCBS MR/DD waiver must meet the following requirements:

- Be licensed by the Kansas Department of Health and Environment as a family foster home, meet all state or SRS/CFP requirements, or be another residential setting that is approved by SRS/HCP;
- Serve no more than two (2) children unrelated to the family foster care provider; and
- Be located in or near the child's home community and school so the child remains in contact with the natural family, if appropriate, and maintains established community connections such as but not limited to: the child's school and teachers, friends and neighbors, community activities, church and health care professionals.

These stipulations apply whether or not the child is voluntarily placed in the family home or is placed in a family foster home as a result of being placed in SRS custody by the Children and Family Services Foster Care Contractor. Persons 18 to 22 years of age may be served in either Adult Residential Services or Children Residential Services, whichever is most consistent with the person's preferred lifestyle.

Infants and toddlers (age 0 to 3) may be evaluated for Part C, early intervention services if it is suspected the child has a developmental concern or delay or if the child has a diagnosis which has an established risk for developmental delay. Part C services consist of educational and therapeutic interventions and can be accessed through local community infant/toddler programs. CDDO representatives can offer assistance in referring individuals to these programs.

Children age 3 to 5 may access Part B, early childhood special education services. A child may either transition from part C to part B services or may start with part B services. Part B services are offered through the local Special Education Cooperative.

When a student has been evaluated and determined eligible for special education services, an Individualized Education Program, IEP, must be developed for the student. Special education and related services can not begin without written parental consent and having an IEP in place. The services written into the IEP must begin not later than 10 school days after parental consent is given unless reasonable justification for delay is shown.

The IEP is both a process and document. As a document, the IEP is a written statement of the educational program designed to meet the individual needs of the student. It is a blueprint that guides the student's day to day instruction, supports and related services. As a process, the IEP meeting brings together people who work with the student to set goals, resolve challenges and develop a plan for the student's education. The IEP has two general purposes: 1) to set reasonable goals for the student; and 2) to state the services that the school district will provide for the student.

An Individualized Family Service Plan (IFSP) is written for children with exceptionalities, birth to 3 years of age. An IEP is required for students ages 3 through 21 with exceptionalities who need special education services. For children 3 through 5 years of age, an Individualized Family Service Plan (IFSP) may be used instead of an IEP, if the student's team is in agreement. When the child

turns three years of age and is still in need of special education supports, they would transition to a preschool program for children with disabilities. The meeting to develop a student's first IEP must be held within 30 calendar days after the student is determined eligible for special education services. Thereafter, the IEP must be reviewed at least annually to review the student's progress, develop new goals and objectives and determine if changes need to be made to the special education and related services currently received by the student. In addition, a parent or other member of the IEP team may ask for an IEP meeting any time during the year. The IEP team must consist of the parent, student when appropriate, at least one of the student's special education and regular education teachers, a representative of the school who is qualified to supervise the specially designed plan, knows the curriculum and the school's resources and any members of the evaluation team to interpret instructional implications of the evaluations and others as appropriate. With parental consent, additional IEP members may include; advocates or relatives invited by the parent or student, case manager, other people who work with the student such as a job coach, bus driver, para-professional, school nurse, etc. If it is a transition IEP, other community service provider agencies will be invited also. (It is a good idea to let the school know who is coming to the IEP meeting, in advance.)

The IEP must contain the following statements:

- Student's present level of performance - how the student is currently doing in school.

- Annual goals - what is to be accomplished within the year of the IEP, including objectives or benchmarks to reaching these annual goals.
- Special education and related services to be provided - this includes supplementary aids and services and any changes to the program or supports needed for the student.
- General education participation - how much of the school day will the student spend educated separately from non-disabled peers or not participate in extracurricular or other nonacademic activities such as lunch, clubs, etc
- Participation in state and district-wide assessments - what, if any, modifications or changes are needed in order to take these assessments or if it is not appropriate to take the assessments, why and what alternatives will be used.
- Dates and location - when services and modifications will begin, how often they will be provided, where they will be provided and how long they will last.

- Measuring progress - how school personnel will measure progress toward IEP goals as well as how this information will be shared with the parents.

Note: It is important to recall that any child who receives any MR/DD service beyond direct financial support/subsidy (periodic cash payment) must have a person centered support plan (PCSP) which includes the elements of KAR 30-63-21. It is very appropriate to incorporate the PCSP – both process and document – with the IEP or IFSP discussed above. Sometimes this works very well and is a natural, efficient approach to combining both sets of issues/needs. However, if that does not work for any reason, the case manager should help ensure that a separate PCSP – which may incorporate provisions of an existing IEP/IFSP – is developed and implemented.

Under the Individuals with Disabilities Education Act, IDEA, transition services are defined "as a coordinated set of activities for a student with a disability that —

- is designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, or community participation;

- is based upon the individual student's needs, taking into account the student's preferences and interests; and

- includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation."

Transition planning focuses attention on how the student's educational program can be planned to help the student make a successful transition to their goals for life after high school.

At the age of 14, or earlier if appropriate, the IEP team is required to look at the future, post high school plans of the student and set a course of study with appropriate goals and objectives to enhance the student's skills for success, all based on the student's preferences and interests. The IEP then becomes a Transition IEP.

At the age of 16, actual transition services are provided in a wide range of areas, including assigning other interagency responsibilities and needed linkages as part of the IEP goals. (application to post secondary schools or other adult agencies for services, etc.)

At least one year prior to reaching the age of 18, the school must ensure that the student and parents have been informed that the rights of majority will transfer to the student upon reaching the 18th birthday.

Special education services must be provided in the Least Restrictive Environment (LRE) meaning the educational placement in which, to the maximum extent appropriate, students with disabilities are educated with students who are not disabled.

Special education and related services are provided at no cost to the parents.

The transition team core key members are the parents and the student. The student must be involved in the meeting however, if they are unable to attend, the school must take other steps to ensure the student's preferences and interests are considered in the plan. Other members would include the special and regular education teachers, administrative representative, related support services providers and others as appropriate. In addition, representatives that provide post-high school services should be involved, depending on the future needs of the student. This could include representatives from Vocational Rehabilitation, Independent Living Centers, community MR/DD

service providers, case manager, vocational or post secondary education, community recreation programs, self-advocacy groups, representatives from the local Housing Authority, present or potential employers, mental health service providers, etc., any agency that may be able to provide services to the student before leaving high school as well as in the future.

At the age of 16 or older, Kansas law requires the school to notify Kansas Rehabilitation Services about students who may qualify for or be interested in rehabilitation services. However, Kansas Rehabilitation Services (KRS) has its own eligibility requirements, so not all students receiving special education services can receive KRS services. The IEP team makes the decision if the student is referred to KRS, based on the disability of the student and their future needs. If the notification to KRS is appropriate, a KRS counselor becomes a member of the team and assists with decisions about goals and services.

As a case manager for MR/DD services, some of the responsibilities as a transition team member may be to assist in the completion of BASIS to determine eligibility for services and/or assist with an application for adult services, coordinate the development of a current person-centered support plan, coordinate and assist the family in setting up tours and obtaining information about all available adult service community service provider options, assist with guardianship information or obtain SSI or Medicaid, etc.

As the Transition IEP is developed, designated agencies commit to various responsibilities as part of the transition process both while the student is in school as well as after graduation. If, during the implementation of the transition plan, any agency is unable to fulfill their responsibilities, the team must reconvene to identify alternative strategies. The responsibility cannot be reassigned to another agency without the agency's approval and commitment. The Transition IEP can be changed at any time, as needed to meet the needs of the student.

Review of the Transition Planning Process:
- Identify preferences, interests and needs of the student
- Develop the vision for the future
- Develop Transition IEP
- Implement the Transition IEP
- Evaluate the results and make changes as needed